UiO : **University of Oslo**

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Co-designing cooperative artifacts with MACI people

A study of empowering practices and artifacts in rehabilitation and co-design

Thesis submitted for the degree of Philosophiae Doctor

Department of Informatics
Faculty of Mathematics and Natural Sciences

Østfold University College
Sunnaas Rehabilitation Hospital

2021

Series of dissertations submitted to the
Faculty of Mathematics and Natural Sciences, University of Oslo
No. 2426

ISSN 1501-7710

Cover: Hanne Baadsgaard Utigard.
Print production: Reprosentralen, University of Oslo.

To my dad, Vilson Çarçani, whose memory was the main motivation for starting my PhD journey.
To my mom, Flora Çarçani, who motivated me every day of this journey with her wisdom, smile, and her confidence in me.

ABSTRACT

This thesis explores empowerment in two equally important contexts. First, patient empowerment in rehabilitation. Second, empowerment of people with Mild Acquired Cognitive Impairments (MACI) in Participatory Design (PD) sessions to co-design cooperative artifacts for MACI's empowerment in rehabilitation. Empowerment in this thesis is understood as a compound of outcomes, practices, values and artifacts.

Patient empowerment is a central subject in a rapidly changing healthcare system. Empowerment discussions are usually focused on outcomes and less on empowering practices. Attention is mostly on the patient and less on emphasizing the necessity of cooperation and services co-construction with their healthcare practitioners. In this thesis, a Computer Supported Cooperative Work (CSCW) perspective was applied to study patient empowerment in rehabilitation as cooperative work negotiated between patients and healthcare practitioners. Empowering practices and implications for design of empowering artifacts were explored. The practices and artifacts are meant to contribute to patient participation in decision-making regarding care, understanding and having control of their own care process, while cooperating with healthcare practitioners.

Patient empowerment in rehabilitation has been studied in the case of MACI patients cognitive rehabilitation. Designing cooperative artifacts that support empowerment of power weak group(s) in a cooperative space benefits from empowering that group also in the co-design of such artifacts. MACI people has been overlooked in the PD literature where the focus has been on much severe cases. Hence, this study focuses on empowering practices and empowering artifacts that contribute to MACI people having a say, influencing decision-making and influencing design outcomes in co-design of cooperative artifacts that support their empowerment in the care process.

A PD and ethnographic approach has been used to collect data in four research blocks. The data gathered has been analysed using different interpretive hermeneutic methods. This thesis contributes to the field of PD by involving a marginalized group in co-design. Further, it contributes to the field of CSCW by applying its concepts in a new context, and finally brings both fields together in the pursuit of empowerment.

PREFACE

This study is submitted in partial fulfilment of the degree of philosophy doctor at University of Oslo (UiO), the Faculty of Mathematics and Natural Sciences, Department of Informatics. The work done for this study has mainly been performed and as parts of the research activities at the Faculty of Computer Science, Østfold University College, Department of Informatics, University of Oslo and Sunnaas Rehabilitaton Hospital, the Cognitive Rehabilitation Department.

Klaudia Çarçani
Oslo, August 2021

ACKNOWLEDGEMENT

Jumping in such a long and explorative journey in our life means having close people that support and motivate you to be the best version of yourself. While in the journey, the network of people that push us further becomes wider, and we get to know wonderful people that also contribute to our lives in a significant way. I have been lucky to have had both my safety net and known new people on my way.

I want to initially start my thanks to my "home" for the last four years, the Østfold University College. I want to initially thank all my colleagues who have made me always feel part of the group, get the needed dosage of positivity and motivation during our lunch breaks. My warmest thanks go to my colleagues from the Interaction Design Group, specifically Assoc. Prof. Joakim Karlsen, Assoc. Prof. Susanne Stigberg, and Marius Akerbæk. I am grateful to have shared knowledge, workload, and a lot of friendly discussions with you. I want to also thank Assoc. Prof. Monica Kristiansen Holone, our study leader, for creating all the opportunities for me to have my dedicated time for research. Your skills with students have contributed to make me grow as a lecturer. I want to also thank Prof. Ricardo Colomo-Palacios, for being additional guidance through my journey and for all the explosive energy that you transmit. Above all, at HiØ I want to thank my main supervisor Assoc. Prof. Harald Holone. Thank you, Harald, for being my biggest support through this journey. The hours spent together discussing, co-writing, co-analyzing, co-reflecting have contributed significantly to my academic growth. You have not only been a wonderful supervisor but also a great leader to motivate, support and appreciate me at any time. Without you, this journey would not have been the same.

The second place where I have spent a significant part of my PhD is the venue where I conducted my research, Sunnaas Rehabilitation Hospital. I want to initially express my gratitude to all the participants in my study, both patients and staff at the Cognitive Rehabilitation Department. I want to thank specifically Geir Ove Karlsson the previous leader of the Cognitive Rehabilitation Department, who welcomed me and guided me through my research. Our discussions are an important part of my study but also have been

a source of motivation for me. I also want to thank Cecilie Hamnes and Victoria Nestaas Vogt, who contributed to keep on the drive and desire for change as in the project start. I want to also thank you Bjørn Kleven, for the long discussions that have contributed to broader the perspective of my research. I also want to thank Tuva Merete Glende Nitteberg for joining me as a second facilitator in three of my workshops. Your presence made a difference. My special thanks go to Ingvild Tormodsdotter Nes, my main collaborator throughout all my study. You have been a major pillar through my PhD journey by supporting me in all the projects with your extensive knowledge, enthusiasm, and positivity. I am grateful to have shared this journey with you. Finally, I want to thank my Sunnaas supervisor, Assoc. Prof. Frank Becker for all your support in facilitating my research at Sunnaas. Our discussions, your medical viewpoint, and the literature that you have introduced me in the field of rehabilitation and cognitive rehabilitation stand at the core of this thesis, and for that, I am very grateful.

The third venue where I have also spent a big part of my research time is the Design Group at the Institute for Informatics at the University of Oslo. I want to thank every member of the group for making me feel welcomed every time I was in the office and with whom I have shared discussions that have been relevant in the course of my study. I want to thank Prof. Tone Bratteteig as my co-author and co-ideator of one of the main contributions in this thesis and a mentor in the field of CSCW and PD. I also want to thank Senior Researcher Diana Saplacan who has been a wonderful co-worker and friend for me during my PhD. I am happy to have met you in this journey. Many thanks to all the PhD fellows that I have shared my journey with, Amin Shahraki, Alize Franz, Rebekka Soma, Johanne Oskarsen, Trenton Schulz, Selina Demi and Marius Geitle. I want to also thank my co-writer Assoc. Prof. Miria Grisot for her advices and getting an interests into my research. Finally, I want to thank Assoc. Prof. Jo Herstad, my supervisor at UiO for all those interesting ideas that we shared together. I am grateful for all the support in facilitating every relation I had at UiO and being always there with a door and mind open to discuss new ideas, explore new angles, and make the best out of my research. Many times you have introduced me to new concepts and theories that have been fascinating and inspiring for me.

As I stated at the start, more people have supported me in different ways. I want to especially thank the person who has been my promoter, motivator, and inspiration for starting my PhD and throughout all my journey, Prof. Christina Mörtberg. Thank you for all your support in all the ways through all these years. How you care for your students at any time in their career is unique, and I cannot be grateful enough. I want to also thank specifically my friends Selda - you always know how to make me feel better since forever now, and Irmina - for sharing part of your infinite care for the world with me. Thank you both for being there to support me and be a source of motivation to refill my energies anytime I needed. I want to thank also all my close friends in Albania and Brussels. Meeting with you has been a break from the intense workload.

Jeg vil gi en stor takk til min beste venn Anders for å støtte meg, motivere meg, og stole på meg. Takk for å være den fantastiske personen du er og den jeg kan diskutere om alt i verden. Takk for alle de eventyr vi har opplevd sammen i disse årene og de koslige kveldene etter en lang dag på jobb.

And now I want to thank those to whom I dedicate everything, my family. My little sister Anxhela who is the joy of my life - Xheku zemra motres faleminderit per te gjitha te qeshurat dhe detyrat qe me ke dhene gjate ketyre viteve. Me kane bere me te lehte qe te shkeputem nga vorbulla e puneve dhe te relaksohem me gjera te tjera. Ti je energjia ne shpine tone dhe vetem nje mesazh i joti gjate dites mua me ben me te lumtur.

Above everyone, I want to say thank you to my mum, mentor, role model, and biggest love Lola Carcani – Mamushja ime ti ke qene shtylla ime gjate gjithe ketij udhetimi jo vetem si nene, por si shoqe, si intelektuale, si grua. Oret e gjata qe kalojme bashke cdo dite jane pjesa me e bukur e dites time dhe frymezimi kryesor per te vazhduar me tej ne rrugetimin tim. Dashuria, kujdesi, vemendja jote me kane bere te heci e sigurt ne cdo hap ne jete dhe te njejten gje ke bere gjate doktoratures. Nuk ka fjale te pershkruaj mirenjohjen dhe dashurine per ty. Faleminderit qe je themeli i familjes sone dhe qe me ben te ndjej ty dhe babin gjithmon prane ne cdo moment dhe nuk harron kurre te me thuash sa krenar te dy jeni per mua. Kjo doktorature te dedikohet ty the babit ashtu sikurse ju kisha premtuar.

LIST OF PAPERS

Paper I

Çarçani, K., Herstad, J., and Holone, H. (2019). Making activities visible: a way to patient empowerment. In Proceedings of the Halfway to the Future Symposium 2019. pp. 1-7

Paper II

Çarçani, K., Holone, H., Becker, F., and Herstad, J. (2020) Understanding work organisation in rehabilitation: A workplace study of cognitive rehabilitation. (status: submitted)

Paper III

Çarçani, K., and Holone, H. (2020). Guidelines for Participatory Design with People Living with Mild Acquired Cognitive Impairments. International Journal on Advances in Intelligent Systems. ISSN 1942-2679. 13(1&2), pp. 59-84

Paper IV

Çarçani, K. and Holone, H. (2019). A Participatory Design "Method Story": The Case of Patients Living With Mild Acquired Cognitive Impairments, ACHI 2019, The Twelfth International Conference on Advances in Computer-Human Interactions. ISBN 978-1-61208-686-6. pp. 210 - 217

Paper V

Çarçani, K., Bratteteig, T., Holone, H., and Herstad, J., (2020). EquiN: A method to balance power relations in participatory design - Designing cooperative digital solutions for people with cognitive impairments. The Journal of

Collaborative Computing and Work Practices. (status: under revision - the paper was recently suggested for major revision)

Paper VI

Çarçani, K., Grisot, M., and Holone, H. (2020). Designing Personal Health Records for Cognitive Rehabilitation, In (ed.), ACHI 2020, The Thirteenth International Conference on Advances in Computer-Human Interactions. International Academy, Research and Industry Association (IARIA). ISBN 978-1-61208-761-0. konferanseartikkel. pp. 250 - 259

Paper VII

Çarçani, K. and Holone, H., "Boundary Objects or Coordination Mechanisms?" (2019). Selected Papers of the IRIS, Issue Nr 9 (2018). 4. Available at: https://aisel.aisnet.org/iris2018/4

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ACRONYMS

ABI	Acquired Brain Injury.
ADL	Activities of Daily Living.
AT	Assistive Technologies.
CIS	Common Information Space.
CRD	Cognitive Rehabilitation Department.
CSCW	Computer Supported Cooperative Work.
EMR	Electronic Medical Record.
GP	General Practitioner.
HCI	Human Computer Interaction.
ICT	Information Communication Technology.
MACI	Mild Acquired Cognitive Impairments.
OT	Occupational Therapist.
PD	Participatory Design.
PHR	Personal Health Record.
PT	Physical Therapist.
RP	Recovery Pathway.
TBI	Traumatic Brain Injury.

Part I

Part I - Research frame

CHAPTER 1

INTRODUCTION

> "To begin is the most important
> part of any quest and by far the
> most courageous."
>
> *Pluto*

This doctoral thesis is about *finding empowering practices and co-designing empowering artifacts* in two interrelated contexts: 1) patient empowerment in the rehabilitation process and 2) empowerment of the patients in the co-design process of cooperative artifacts. Such artifacts are to be used between patients and healthcare practitioners to support the empowering practices in rehabilitation. The patient group studied is people with Mild Acquired Cognitive Impairments (MACI) in cognitive rehabilitation. I have co-designed with the MACI patients cooperative artifacts to be used between them and their healthcare practitioners in rehabilitation. This has contributed to my explorations of practices for empowering patients with MACI in the co-design process and in exploring empowering practices and implications for empowering artifacts for patient empowerment in rehabilitation.

The co-design process allowed me to investigate patients' and rehabilitation therapists' narratives on empowering practices that contribute to patient empowerment in rehabilitation. Patient empowerment is considered in terms of *participation*, *understanding*, and *control* of the patients over their rehabilitation process. Empowerment in co-design is considered as MACI people *"having a say"* and *"influencing decision-making and the design outcome"* of the co-design process. Disentangling empowerment in terms of outcomes for an empowered patient in rehabilitation or in co-design is rooted in patient empowerment (Chiauzzi et al., 2016; EPF, 2015; Palumbo, 2017; Umar and Mundy, 2015) and co-design literature (Bratteteig and Wagner, 2016a, 2014; Bratteteig et al., 2016; Bratteteig and Wagner, 2016b).

Let us start!
One of the main pillars of society is the healthcare system. Despite still having a core value caring for people's health, how the care is given and received has changed. It has changed due to modern medicine developments, but it has also changed regarding how the system is organized and what care constitutes of, and what role the patient has in the care process. Hence, healthcare is not only about treatment of the acute illnesses but also about looking at the patient's private subjective sphere under a more holistic approach to offer care. This has brought up discussions about the patient role in their care, and the relevance for a paradigm shift (Anderson and Funnell, 2005) in a paternalistic healthcare environment found in the traditional medical model (as Anderson (1995) calls acute care settings). Hence, Anderson (1995) discussed "patient empowerment" as the answer to the paradigmatic shift need in healthcare.

Patient empowerment has been widely researched and has become an important discussion topic concerning law and healthcare regulation. The patient empowerment discourse is recognized as an "essential element of high-quality healthcare systems with regard to tackling the expanding burden of chronic diseases" (EHP, 2015). There are different definitions of patient empowerment, but most researchers agree that it serves as an umbrella term for a set of elements that would contribute to empowering the patient. I will focus attention to one definition created by the European Patient Empowerment and Centeredness Committee (EHP, 2015). As stated above, there are different definitions, and I will elaborate on this more in Chapter 3. However, this definition is a good summary of the patient empowerment discourse:

> "empowered patients... are people who are expected to take more control over their illnesses or treatments where possible, and doctors are expected to encourage or 'empower' them to do so by enabling patients to become equal partners in the team managing their health." (EHP, 2015, p. 3)

The quote above addresses *empowered patients*. Hence, it seems like empowerment is an outcome. Instead, the definition itself describes more practices and processes of the relationship between patients and their carers to enable patients to become "equal" and partners in managing their health and, consequently, becoming empowered patients. So, in the start of the definition above, empowerment is referred to as the outcome. But, in the rest of the definition it is described more as practices that would contribute to the outcome.

The European Patient Empowerment and Centeredness Committee (EHP, 2015) continues describing some characteristics of an empowered patient such as:

- have the necessary knowledge, skills, attitudes, and self-awareness about their condition to understand their lifestyle and treatment options and make informed choices about their health;

- have the capacity to become ’co-managers’ of their condition in partnership with healthcare professionals, with the aim of managing their condition when necessary and also to the extent they wish to do so, because choosing to not be empowered is also considered as a form of patient empowerment;
- have control over the management of their condition in their daily life;
- ideally, have the capacity to develop the self-confidence, self-esteem, and coping skills needed to manage the physical, emotional, and social impacts of their disease or condition in everyday life.

While these are all fair points that would characterize an empowered patient, they highlight two problems in the patient empowerment literature. First, patient empowerment is often described in terms of desired outcomes and less on "how to" get to the outcomes. Second, the concept "patient empowerment" has "patient" involved in the term and the outcomes are described in terms of an empowered patient. The relevance of the cooperation between patient and healthcare practitioners and having engaged healthcare practitioners in patient empowerment is overlooked.

However, in the list above, "co-management", "partnership", "gain skills and knowledge" indirectly relate to the work that the healthcare practitioners should put in to make these outcomes possible for the patient. To gain skills and knowledge a patient needs coaching, and to be able to make decisions, s/he needs to understand. So, patients and healthcare practitioners need to cooperate. This necessity for cooperation is usually overlooked in patient empowerment studies where (in a way understandable) the stress is put only on the patient, and the healthcare practitioners are seen as fitting a patient-led agenda. Palumbo (2017) in his book titled "The bright and the dark side of patient empowerment" states that if the cooperation is not discussed and negotiated from the perspective of patients and healthcare practitioners, it will lead toward value de-construction in the healthcare sector, and healthcare practitioners will not embrace the changes in the patient role due to empowering practices.

The empowerment outcomes highlighted above are relevant as they help disentangle the empowerment concept and make it easier to investigate practices that can contribute to such empowerment. In this thesis, patient empowerment is considered as patient and healthcare practitioners cooperating to make the patient more involved in decision-making regarding her/his care, increase understanding of her/his care process, and patient having control of the care process. This stand point comes from analyzing the existing literature in patient empowerment, presented in-depth in Chapter 3.

Empowerment as a concept is complicated. It is not uncommon that in discussing empowerment, the emphasis is on outcomes or the individual. It seems like researchers, groups of people, societies are in continuous pursuit of empowerment. The same has been with its definition. Empowerment has been discussed and studied both as a result and a process toward the result. In this thesis, "empowerment" theory is drawn from Zimmerman and Warschausky (1998), where empowerment has been defined both as a multilevel and multidimensional concept. They described three dimensions of empowerment: values, processes, outcomes, and three levels: individual, organizational, and community. Zimmerman and Warschausky (1998) argue that the three dimensions are equally relevant when studying empowerment. Empowering processes contribute to empowerment outcomes in an environment where the empowerment values prevail. While Zimmerman and Warschausky (1998) use the term processes, I have found the term delimiting. Hence, in this thesis, I have adopted the concept *"practices"*, referring to more situated empowering activities which are flexible in relation to the situation at hand.

In this thesis, Zimmerman and Warschausky (1998) empowerment theory serves as a framework for defining and positioning the research. This thesis focuses on exploring empowering practices empirically due to the narratives of those involved in the empowerment process and defining the empowerment outcomes from theory and previous research.

However, Chiauzzi et al. (2016) found that there are differences in empowerment levels across diseases and suggests that more investigation on disease-related attributes of empowerment would be relevant. Thus, in this thesis, the focus is on patient empowerment in rehabilitation, narrowing down in this way the scope of the research.

Rehabilitation is "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (WHO, 2011a). Rehabilitation aims to enable individuals with limitations in functioning in everyday life due to a change in health associated with a clinical condition, to participate in education and employment, remain independent, and reduce the need for financial and caregiver support. Rehabilitation is not a luxury, optional service, or a fallback strategy if preventative or curative interventions fail. Rather is a central pillar of effective health care. Rehabilitation has been associated with conditions that lead to changes in people's physical or cognitive abilities. However, it is becoming more and more part of a holistic approach of care for the patients after they have left the acute healthcare setting for different clinical chronic conditions such as cardiac problems (Varnfield et al., 2011; Särelä et al., 2009), lung issues, diabetes (Storni, 2014), etc.

The patients' involvement in their rehabilitation is a strong contributor to increasing the chances of success for rehabilitation (Wilson et al., 2009). Hence, practices that encourage patients to be more involved and in control of their rehabilitation are common in rehabilitation settings (Wilson et al., 2009). However, Wikman and Fältholm (2006) found that while patients "are told to be empowered in the process", empowering practices lack or are not implemented in the right way to deliver the desired result. Hence, making it interesting to study patient empowerment in rehabilitation for two reasons. First, current rehabilitation practices can help understand how to operationalize patient empowerment and serve as best practices for other healthcare contexts. Second, there is a need for empowering the patient in rehabilitation that is not entirely fulfilled in the current practices and can be enhanced.

Patient-driven technology solutions has been shown in research to have a high potential to support patients' empowerment and adoption of an active and responsible role of the patients in their health (Bedlington, 2016). Crook et al. (2016) argue that information technologies improve the ability of the patients to obtain, process, understand and use health information. Fortney et al. (2011) add that technology increases patients' willingness to be actively engaged in the provision of care, creating a supportive and shame-free environment, which encourages the patients to partner with the healthcare professionals to co-create value. Scholars have also emphasized the role of information technologies and digital tools in facilitating the patient-provider relationship and encouraging patients to actively participate in co-planning, co-designing, and co-delivering health services (Calvillo et al., 2015). Information Communication Technology (ICT) as a special technology group is considered as having the potential to increase patient's processing abilities and promote a partnership between patients and healthcare practitioners (Wald et al., 2007). ICT usage has been argued to create greater opportunities for collaboration and health services' co-production between patients and care providers (Eysenbach, 2008).

In this thesis, I have investigated the design implications for such ICTs to be used in rehabilitation by both a patient and her/his healthcare practitioners. The ICTs should support cooperation throughout the care process and patient participation, understanding, and control of the process. In the thesis, I use the term "cooperative artifacts", to refer to traditional artifacts such as paper documents or computational artifacts such as Electronic Medical Record (EMR) system or Personal Health Record (PHR) systems meant to support cooperative work.

In order to investigate the cooperative practices between patients and healthcare practitioners and the design of cooperative artifacts that would support such cooperation for empowerment, I rooted my understanding and analysis of the cooperative work practices in Computer Supported Cooperative Work (CSCW).

CSCW is the field concerned with understanding cooperative work to design adequate computer systems (Schmidt and Bannon, 1992). CSCW studies in healthcare have contributed to advancing the understanding of cooperation between healthcare practitioners and designing different types of technology for work coordination between practitioners (Fitzpatrick and Ellingsen, 2013). In this thesis, CSCW concepts are used to make sense of the patient–healthcare practitioners' cooperation in rehabilitation and to analyze the articulated needs from both parts in terms of empowering practices. More recent research in CSCW has also been done regarding the cooperation and coordination between patients and healthcare practitioners (Vassilakopoulou et al., 2019; Piras et al., 2019; Cabitza and Gesso, 2014). However, in this thesis, the central focus is the "empowerment" of patients, and this empowerment is seen as happening in the cooperation space between the patient and her/his care and making use of CSCW artifacts as empowering artifacts. The discussion of power issues in the cooperation and the design of computer support for cooperative work when one of the cooperating groups seeks empowerment, is less studied in CSCW (Bratteteig and Wagner, 2016a; Kensing and Blomberg, 1998).

European Patient Forum (2015) highlights the need for a change in culture in order to design healthcare around patients' needs. They state that:

> "Empowered patients can be seen as a threat by some health professionals, but what patients seek – and what health professionals need to accept – is simply a change in the balance of power to recognize chronic patients as experts in their own care by experience...Only the patient sees his/her whole journey through the healthcare system, so involving patients in the designing of healthcare systems results in services that meet the real needs of patients."

Hence, they promote patients' involvement in the design of empowering practices and empowering artifacts. However, they also emphasize how relevant it is that healthcare practitioners accept and respect the patient role and the patient part in the care process. Thus, both patients and healthcare practitioners should be involved in the study investigating empowering practices in rehabilitation. The same requirements are also relevant in the design of cooperative artifacts.

Despite the recognized role of technology in patient empowerment, patients who use technology for disease management are a minority, and they often do not find it easy to know which tool would be right for them. The lack of trust and lack of training (European Patient Forum, 2015) have been identified as key barriers to new technology uptake. Often, patients are not consulted in developing the "innovation", and there is no evidence that the new artifacts meet their needs. Technologies claiming to empower patients, in most cases, do not have a significant influence (Bedlington, 2016). These technologies seem to not recognize what real patient needs are and tackle those needs. This can be a consequence of the lack of patients' voices in the design of such technologies.

Thus, to deliver technologies that aim at patient empowerment while in use, involving the patients in the design process can be crucial in the discussion, conceptualization, design, and development of the technologies (Palumbo, 2017). However, to discuss cooperative work and design ICTs that would support the cooperation between patients and healthcare practitioners needs both groups to be involved in the co-design process.

Patients' involvement in co-design sessions and especially together with their healthcare practitioners opens up another issue - empowering the patient in the design process. Healthcare practitioners have more overall knowledge regarding the treatment and the illness journey than the patient. Moreover, healthcare is inherently paternalistic because patients are vulnerable, and healthcare practitioners take care of them. In co-design, the imbalance in power can weaken the patient voice and their ability to influence in the decision-making regarding the cooperative empowering practices and the design of empowering artifacts. Hence, empowering patients in the co-design process will make them discuss their empowerment in rehabilitation from a stronger position and, consequently, influence the cooperation and cooperative ICTs.

People with Mild Acquired Cognitive Impairments (MACI) is the group for whom I explore the empowerment in co-design in this thesis. MACI people get cognitive impairments after having had an Acquired Brain Injury (ABI). ABIs are brain injuries acquired after birth as a consequence of Traumatic Brain Injuries (TBI) (such as accidents, falls, and assaults) and Non-Traumatic Brain Injuries (non-TBI) (such as stroke, brain cancer, aneurysm, etc.). Some of the cognitive challenges associated with MACI are: problems with memory, attention, fatigue, perception, affection, social interactions, executive functioning, behavioral, etc. MACI people usually do not have physical disabilities, which is why this is called "the silent epidemic". Their problems are mild, but they influence the lives of these people in a drastic way. "There are so many things that I can't do now that I could do before," said one of the participants in my study. She concluded, "because at the end we are all sick," referring to the others in the same position. Hence, there is a challenge for MACI people to participate in co-design because co-design is a demanding process on the participants' cognition. This adds to the imbalance of power. Thus, we need to find ways to make MACI people empowered in the co-design process. Such findings can then contribute to other groups that share similar symptoms with MACI people.

Participatory Design (PD) is the field concerned with users' genuine participation in the design of technologies meant for them and with power imbalances in the design process (Simonsen and Robertson, 2012). I have used Participatory Design as an approach to investigate the patient empowerment practices in rehabilitation and the design of the cooperative ICTs. Moreover, PD is the field where I have drawn my study on the empowerment of MACI people in co-design and contribute with the empowering practices in co-design for this specific user group.

The participation of users with cognitive impairments in the co-design process has been discussed previously in PD literature (Bratteteig and Wagner, 2016a, 2014). However, the extensive studies are mostly on more obvious and severe cases such as dementia, aphasia, amnesia etc., or PD studies of elderly people that represent a more degenerative situation. MACI people are not old, have had a life without impairments before, and have hope to become better. However, as every patient group when involved in co-design with their healthcare practitioners, a imbalance in power is created, coming from differences in knowledge, from a parent-child relationship between them, and in the case of MACI patients from differences in their cognitive abilities. Hence, in this thesis, some practices on how to empower MACI people in the co-design of cooperative artifacts to be used with their healthcare practitioners are presented.

In conclusion, the thesis has two main interrelated parts: 1) patient empowerment practices in rehabilitation and 2) empowerment practices for MACI in co-design. The patients involved in the study are people with MACI, and the healthcare context is the one of rehabilitation. The empowerment of patients in the co-design process contributes to the discussion and design of empowerment practices and empowering artifacts in rehabilitation. The empowerment of patients in rehabilitation provides a context for exploring the empowerment of MACI patients in co-design within the group and also together with their carers. Patient empowerment in this thesis is seen as happening in the cooperation space between a patient and her/his carers, where the patients are motivated to participate, understand and take some control of their illness journey. In rehabilitation, strengthening the patient's position in cooperation with their care is relevant and can influence the outcome of rehabilitation.

1.1 Motivation

The motivation for researching empowerment in rehabilitation stems from the collaboration with Sunnaas Rehabilitation Hospital. Sunnaas operates in Norway and offers specialized rehabilitation programs operating in Norway. Sunnaas has a strong interest in patient empowerment in rehabilitation and is home to different research projects that can improve their rehabilitation services. The interest in empowerment in co-design stems from my own background in Participatory Design and applying democratic practices in research.

There has been an increase in interest in rehabilitation services over the last decades. This stems from an increase in the number of people in need of rehabilitation. Moreover, rehabilitation is becoming an integral part of a holistic perspective of treatment that goes beyond curing a specific clinical condition and considers a patient's quality of life on the verge of chronic conditions. The increase in the number of patients that need rehabilitation comes due to the improvements in medical treatment and healthcare systems resulting in higher survival rates from disease and injury, with many people continuing to live with some form of residual impairment. Another reason is the rising prevalence of non-communicable diseases and the demographic changes of an aging population. WHO estimates that individuals aged over 60 will double by 2050, and there has been an 18% increase in the prevalence of non-communicable diseases in the last 10 years (WHO, 2020).

In WHO (2020) rehabilitation fact-sheets site, says that around 2.4 billion people are currently worldwide living with some form of the condition that can benefit from rehabilitation. In the WHO European Region member states, 6 - 10 out of every 100 people live with a disability (ibid). However, with population aging and the rising prevalence of chronic conditions due to non-communicable diseases and injuries, this number is set to increase in the future (WHO, 2020).

Thus, rehabilitation is a part of healthcare that is evolving, and studies on this specific part of healthcare can have an important impact. Patient empowerment in rehabilitation can contribute to the success of rehabilitation. There are current practices that promote patients' involvement in their rehabilitation. However, there is still space for improvement before defining patients empowered in rehabilitation. Thus, rehabilitation settings are still looking for empowering practices for their patients. Sunnaas is in such a position.

Another characteristic that makes rehabilitation interesting to study is that in rehabilitation, patients work with a team of therapists. How well the patient cooperates with the team and how much s/he controls the rehabilitation process influences the rehabilitation outcome. Studying rehabilitation is interesting as there are already existing empowering practices that may be considered from other healthcare settings.

A central part of my study are people suffering from MACI after an ABI. The level of symptoms after and ABI can variate from mild to severe. As the name states, MACI refers only to the mild cases, which are also the most invisible ones.

From 70 to 90% of all hospital-treated brain injuries are mild TBI (MTBI). In Norway, 86% of cases of hospitalization for a TBI were classified as mild TBI, accounting for an average of 9 000 people experiencing mild TBI and in need of hospitalization each year (Vikane, 2016). The non-TBI cases have increased with a higher number of patients surviving strokes and having to leave with some form of cognitive impairment. Development in medicine has contributed to decreasing the mortality rate from stroke. This means that more people surviving stroke have to face a life with some consequences coming from stroke and be involved in rehabilitation to be able to improve or compensate for their condition.

As stated above, mild ABIs are called the silent epidemic because people suffering from MACI have struggles in daily life, but they have in most cases no physical sign showing their disability and can be easily confused with other symptoms. Hence, in IT and design research, this user group has been overlooked, and the attention had been on more severe cases. Considering the large population with MACI and the lack of representation of their voices in the design of technologies meant for them, I was motivated to study how to involve this user group in Participatory Design.

While the topic was proposed initially by a more managerial position at Sunnaas, the same concerns regarding the need for further empowerment of the patients in their rehabilitation process and the need to empower the MACI patients in co-design were also confirmed once I started the study and entered in contact with patients and staff working at Sunnaas. Thus, what is presented in this thesis started as a project with the initiative of Sunnaas management, then I wrote it into a research project, and it took final shape once I started the research project and heard the voice of both MACI patients and healthcare practitioners at Sunnaas regarding their concerns and needs.

1.2 Empirical Study

To carry out my investigations, I studied the process of cognitive rehabilitation at Sunnaas Rehabilitation Hospital. Thus, I conducted my research in a Norwegian context, where the view on patient empowerment is situated in enhancing patient participation in their care. It is relevant to emphasize the Norwegian context as the rehabilitation offered and the perspective on empowerment differs from other parts of the world.

Within rehabilitation, I studied the cognitive rehabilitation process, a special rehabilitation program offered to people suffering from cognitive impairments after an ABI and which involves training or compensation for the affected cognitive abilities.

At Sunnaas, such a program is offered at the Cognitive Rehabilitation Department (CRD), which is the venue where I conducted my research. My work at the CRD consisted of three research blocks as described below. The Research Blocks had different aims, but each has contributed to answering the research questions raised in this thesis. They have been useful for triangulating the data collected. These are presented in detail in Chapter 5. In Chapter 5, I have an additional Research Block based on a systematic literature review that I have conducted. I have not included it below because is not part of my empirical data.

Research Block 1: The first project is called the "Redesign of the goal plan document". This was an internal project at the CRD initiated by the management of the department. The project aimed to redesign the layout of the goal plan document. The goal plan document is a document that contains information regarding the rehabilitation plan. It is generated in the hospital’s Electronic Medical Record (EMR) and is shared with patients as a paper document. The document helps to coordinate the work between patients and healthcare practitioners in rehabilitation. I was involved in the project as a designer/researcher focused on redesigning the goal plan document to support patient empowerment. I used co-design workshops as a method to collect data. This also contributed to reflect on MACI people’s empowerment practices in co-design.

Research Block 2: Non-participant observations at the CRD. I shadowed some healthcare practitioners in their daily activities and appointments with the patients for some days. This research block aimed to map the cooperative practices in the current rehabilitation process and critically reflect on them in relation to empowerment outcomes. The data collected were handwritten notes. The process helped me as a researcher to see the organization of work and the interaction between patients and healthcare practitioners in detail. This exposed interaction issues that were not captured when the patients and healthcare practitioners talked about their interactions in Research Block 1.

Research Block 3: This project is called "The digital goal plan". It is part of the project “VITAL - för den goda hälsan", financed by the INTERREG Sverige-Norge under the grant number: 20202391 where Østfold University College (HiØ) and Sunnaas cooperate. The project aims to design and develop an application that can be used between patients and healthcare practitioners at Sunnaas to cooperate to define rehabilitation goals and manage the rehabilitation process. In this thesis are reported only the requirement investigation part of the project, and the development process is ongoing.

I used co-design workshops as the method for collecting data for the design of the digital cooperative artifact. Both patients and healthcare practitioners were involved together in workshops. Patients and the healthcare practitioner had the possibility to negotiate their cooperation and how the cooperative artifacts should be to support such cooperation. Finally, the co-design workshops in this project contributed also to studying MACI patients' empowerment in co-design together with healthcare practitioners, where power issues emerge and need to be managed.

1.3 Research Questions

Research questions are relevant to orient the researcher in the research fields (Holter and Kalleberg, 1996, p.34). Saplacan (2020, p. 8) states "while the researcher gets acquainted more in the field can also re-formulate, re-iterate or re-think the questions" states . In my PhD journey, I have re-formulated my questions based on new understanding and terminology that I acquired on the way. However, my main aim corresponding to the research questions has not changed along the way.

Kalleberg (1992) and Holter and Kalleberg (1996) have described three types of research questions, such as: descriptive/constative, normative/critical, and constructive. Descriptive research questions are asked when aiming to explain a situation or condition, interpret and explain something. These may be "how" questions. Normative/critical questions are asked when the researcher wants to evaluate or criticize an existing reality, point out equalities and inequalities, justice and fairness. These questions may be why-questions, challenging existing values, and pointing to power imbalance. Finally, constructive questions ask for alternatives to a present situation or phenomenon, and they often focus on transitions. These questions are what-questions focusing on improvements.

Reflecting on the types of questions presented above, I started my research by asking more descriptive and normative questions. Normative questions pointing to asymmetrical power relations and discussing inequalities are close to the empowerment discourse. However, the research presented in this thesis is more active. It is pointing toward constructing knowledge that can contribute to empowerment. Hence, in this thesis, research questions are what questions. However, in the papers related to each of the research questions of this thesis both descriptive and normative questions have been asked. The same descriptive and normative approach has been adopted throughout the research as well. The constructive questions asked in the thesis represent a meta reflection on the findings presented in the papers from the perspective of the empowerment theory. This thesis presents and discusses findings for the following research questions:

RQ1: *What practices contribute to MACI people empowerment in co-design?*

RQ2: *What practices contribute to patient empowerment in rehabilitation?*

1.3.1 RQ 1

While this thesis's focus is on the empowerment practices, it is initially relevant to define what empowerment in co-design entails in terms of expected outcomes for the power-weak participants. Thus, the first question I ask is, "What does empowerment in co-design entails?" The answer to this question is drawn in the co-design literature. I concluded that participants empowerment in co-design involves the following outcomes: participants having a say in the design process and influencing the decision-making and the design outcome. I have investigated empowering practices through reflections on co-design workshops with MACI patients regarding what they thought would contribute to their empowerment as described in the outcomes.

- **SRQ 1.1:** *What practices or methods contribute to MACI people's having a say and influencing the decision-making and design outcome in the co-design process?*
- **SRQ 1.2:** *What practices or methods contribute to MACI people have a say and influence the decision-making and design outcome in the co-design process of cooperative artifacts with their healthcare practitioners?*

Designing empowering artifacts that support cooperation with the aim of patient empowerment in rehabilitation also requires patients and healthcare practitioners' involvement in the co-design process of these artifacts and their corresponding cooperative practices. However, being involved in designing empowering artifacts cannot be separated from the need to empower the users in the co-design process. This empowerment should be when involved in design as a single user group or when involved in the co-design process with other stakeholders. Only through empowered users during the design process can the groups better negotiate their relationships toward patient empowerment. This has been the motivation for RQ1. This question is an umbrella for the two sub-questions. SRQ 1.1 concentrates on empowering practices and artifacts that can help MACI patients in co-design sessions. The question investigates how to facilitate a MACI person's involvement in co-design space by considering and respecting their cognitive challenges. SRQ 1.2 concentrates on practices or methods for empowering the MACI person in the co-design process with her/his healthcare practitioners, for designing a cooperative artifact that both will use to cooperate on the treatment management. By asking these constructive questions, I am trying to determine what we should as designers and researchers do to empower MACI people in the co-design process. The answers to these sub-questions have been illustrated through findings from Research Block 1 and 3. The answers to these subquestions are presented in Chapter 6, building on the findings presented in Papers III, IV, V included in this thesis.

1.3.2 RQ 2

While this thesis's focus is on empowerment practices, it is initially relevant to define what patient empowerment means in terms of expected outcomes for the patients. I have drawn my understanding of empowerment outcomes on the literature. Thus, the first question I ask is, "What does patient empowerment mean for the patient?" I answer to these questions by reviewing literature on patient empowerment which is presented in Chapter 3. I have concluded that patient empowerment in rehabilitation is related to the following outcomes: patients participating in the care process, understanding it, and gaining control. I have investigated empowering practices through narratives of patients and healthcare practitioners regarding what they thought would contribute to their empowerment as described in the outcomes. RQ2 is an umbrella for the following sub-questions.

- **SRQ 2.1:** *What cooperative practices contribute to make patients participate, understand, and in control of their rehabilitation?*
- **SRQ 2.2:** *What are some implications for the design of cooperative artifacts that support patients participation, understanding and control in rehabilitation when they cooperate in the care process with their healthcare practitioners?*

SRQ 2.1 is focused on defining practices that will contribute to the operationalization of patients empowerment in rehabilitation. Instead, SRQ 2.2 concentrates on the design implication of empowering artifacts that can support and enhance the empowering practices in rehabilitation. As in this thesis, empowerment is seen as laying in the cooperation between patients and healthcare practitioners, the empowering artifacts thus are cooperative artifacts.

By asking these questions, I am trying to understand, qualitatively, what practices should rehabilitation settings and healthcare settings, in general, take into consideration to pursue patient empowerment.

The answers to these sub-questions are illustrated through the empirical findings from each of the research blocks listed above and presented in Chapter 7 of this thesis, building on the knowledge presented in Papers I, II, VI, VII presented in Part IV.

1.4 Limitations

This thesis's limitations are related to the replicability of the findings and the scale of the research. The patient empowerment discourse approach differs in different parts of the world based on the historical, economic, and political realm in which these discourses emerged. Patient empowerment has become a recurring topic of health policies in most western countries.

However, it assumes different meanings and specific characteristics in light of the healthcare system's particular attributes to which it is attached (Palumbo, 2017). In the Scandinavian countries, patient empowerment is focused on the enablement of patients to participate and take some control over their care. Instead, for example, in Eastern Europe and the Balkan countries, patient empowerment is related mostly to the patients' right to access health information. In the US, patient empowerment has been developed along with consumers' empowerment by emphasizing the freedom of choosing their care. While there are interesting factors in every perspective, I am looking at patient empowerment from the Scandinavian countries' perspective aligned with the EU discourse.

The findings presented are based on a Norwegian case. This poses a limitation because, in Norway, rehabilitation practices are already regulated. Norway has a universal healthcare system, and the right to have rehabilitation services is included in the law. In addition, there is a considerable number of healthcare practitioners per patient, making it easier to implement cooperative practices. Moreover, the population has a high immersion of technologies in everyday life. The study and practices presented in this thesis can be used as guidelines that need further customization in practice in other countries.

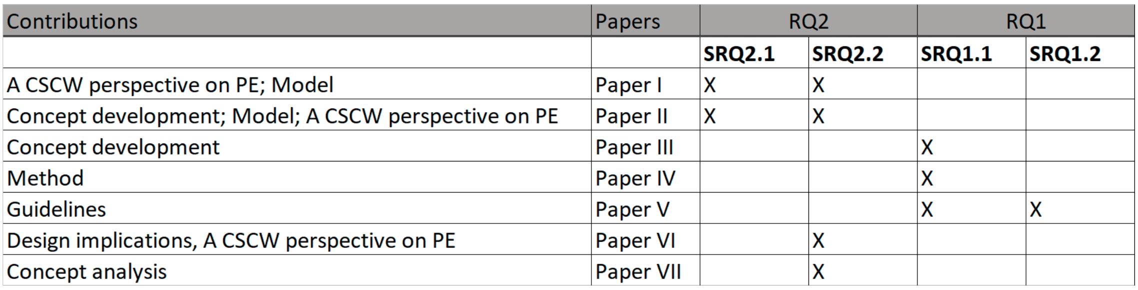
Another limitation is the limited number of MACI patients who have participated in the study, considering that this is a very heterogeneous group. However, my extended period of study at Sunnaas has allowed me with the possibility to meet MACI people and get to know their stories even when they were not involved in my workshops. I have started also listening to the stories of MACI people that had not been at Sunnaas. In this way I have become acquainted with their struggles in their life and how important it is to make heard this "silent epidemic".

1.5 Contributions

This thesis consists of seven papers. Three papers are related to RQ1, and four papers are related to RQ2. Table 1-1 shows an overview of the contributions with their corresponding papers and the research questions they answer. This thesis's main contributions are: empowering practices for patient empowerment in rehabilitation; implications for designing cooperative artifacts to be used between patients and healthcare practitioners in rehabilitation; empowering practices for MACI people in co-design within the group or with other stakeholders.

1.5.1 List of papers

Paper I - Çarçani, K., Herstad, J., and Holone, H. (2019). Making activities visible: away to patient empowerment. In Proceedings of the Halfway to the Future Symposium 2019. pp. 1-7.



Contributions	Papers	RQ2		RQ1	
		SRQ2.1	**SRQ2.2**	**SRQ1.1**	**SRQ1.2**
A CSCW perspective on PE; Model	Paper I	X	X		
Concept development; Model; A CSCW perspective on PE	Paper II	X	X		
Concept development	Paper III			X	
Method	Paper IV			X	
Guidelines	Paper V			X	X
Design implications, A CSCW perspective on PE	Paper VI		X		
Concept analysis	Paper VII		X		

Table 1.1: Relations between research questions, papers and contribution types

Paper II - Çarçani, K., Holone, H., Becker, F., and Herstad, J. (2020) Understanding work organisation in rehabilitation: A workplace study of cognitive rehabilitation. (status: submitted)

Paper III - Çarçani, K., and Holone, H. (2020). Guidelines for Participatory Design with People Living with Mild Acquired Cognitive Impairments. International Journal on Advances in Intelligent Systems. ISSN 1942-2679. 13(1&2), pp. 59-84

Paper IV - Çarçani, K. and Holone, H. (2019). A Participatory Design "Method Story":The Case of Patients Living With Mild Acquired Cognitive Impairments, ACHI2019, The Twelfth International Conference on Advances in Computer-Human Interactions. ISBN 978-1-61208-686-6. pp. 210 - 217

Paper V - Çarçani, K., Bratteteig, T., Holone, H., and Herstad, J., (2020). EquiN: A methodto balance power relations in participatory design - Designing cooperative digital solutions for people with cognitive impairments. Journal of Collaborative Computing and Work Practices. (status: under revision - the paper was recently suggested for major revision on the first submission in the Journal)

Paper VI - Çarçani, K., Grisot, M., and Holone, H. (2020). Designing Personal Health Records for Cognitive Rehabilitation, In (ed.), ACHI 2020, The Thirteenth International Conference on Advances in Computer-Human Interactions. International Academy, Research and Industry Association (IARIA). ISBN978-1-61208-761-0. konferanseartikkel. pp. 250 - 259

Paper VII - Çarçani, K. and Holone, H., "Boundary Objects or Coordination Mechanisms?"(2019). Selected Papers of the IRIS, Issue Nr 9 (2018). 4. Available at:https://aisel.aisnet.org/iris2018/4

1.5.2 A CSCW perspective on patient empowerment

A contribution of this thesis stands in merging the cooperative work supported by technology discourse in the CSCW field with the patient empowerment discourse. While patient-healthcare practitioners' relations have been investigated in CSCW previously, the power imbalances seem to have been overlooked. The same on patient empowerment studies where empowerment is achieved in the cooperation space. This CSCW perspective on patient empowerment is present in Paper I, II, and VI.

1.5.3 Concept Development

Throughout the papers, I have also made some contributions to concept development. I have developed the concept of "recovery pathway," referring to the organization of work in rehabilitation (Paper II) and also the concept of "transition work" and" self-management educational work" referring to types of work in rehabilitation.

In the co-design process, I have contributed with other concepts such as "the teaser of future envisioning" (Paper IV), referring to a special kind of activity in a co-design workshop. Moreover, I have defined the concept of "knowledgeable third party," referring to a new role among facilitators in a co-design project.

1.5.4 Method and Models

Different methods and techniques have been applied for co-designing with MACI people. Some of the methods applied are customization of existing techniques. My contribution stands in the thorough description of the application of the method in the form of a method story (Paper IV)

I have also contributed with a new PD method for co-design with MACI patients and their healthcare practitioners cooperative artifacts (Paper V). This is called the EquiN (Equilibria Nudge) method drawn in the literature. It focuses on the balance of powers in the co-design process by increasing the MACI patients' opportunity to have a say and influence the decision-making and the design outcome.

Models are another type of contribution that can be found in the papers. I have developed an operationalizing model for patient empowerment based on an analysis of the rehabilitation practices from a CSCW perspective and discussed them in relation to patient empowerment outcomes (Paper I). Moreover, I have developed another model for the work organization in rehabilitation by building on the "recovery pathway" concept mentioned above (Paper II).

1.5.5 Design Implications

I have also contributed with some design implications for a cooperative artifact for patient empowerment in rehabilitation. These design implications have been discussed in several papers (Paper II, V, VI), and a meta-review of those is presented as an answer to SRQ 2.2 in this thesis.

1.5.6 Guidelines

When it comes to conducting PD with MACI people, I have contributed with a list of guidelines that designers should consider (Paper III).

1.6 Intended Audience

This thesis addresses mainly academics and designers in the following fields who are concerned with the empowerment discourse:

- PD scholars who are interested in PD practices with people with cognitive impairments.
- CSCW scholars who are interested in understanding new complex cooperative work settings such as rehabilitation. I provide a detailed account of the work dynamic in rehabilitation which can be relevant for CSCW researchers interested in workplace studies.
- Rehabilitation work and Rehabilitation Informatics scholars and practitioners interested in how to organize practices and work in rehabilitation and designing empowering artifacts.
- Moreover, this thesis might also be useful to designers positioned in fields such as Universal Design and Human Computer Interaction (HCI). It also could be a contribution to plans and policies in patient empowerment.

1.7 Outline

Part I - In this part, I initially introduce the thesis in Chapter 1. This is then followed in Chapter 2 by an introduction of the Empirical setting. I start by defining rehabilitation and the rehabilitation process and then move specifically to the empirical case studied.

In Chapter 3, I start by presenting the empowerment theory on which the thesis is based, and the empowerment outcomes for patient empowerment in rehabilitation and co-design drawn in the literature. Moreover, I have reviewed previous research and present the gaps in which this thesis contributes.

In Chapter 4, I have explicitly focused on two research fields in which I build my understanding of the case, PD and CSCW, and I elaborate theoretically on some concepts that have contributed to the analysis of the findings presented in this thesis.

Finally, in Chapter 5, I initially position this thesis in the scientific paradigms and then present the methodology, approaches, and methods taken to collect data and analyze them. I present the research design and the activities of data collection and data analysis for each of the research blocks.

Part II - In this part, I have presented the findings of this thesis structured in two Chapters 6 and 7, corresponding to each of the research questions.

Part III - In this part, I have discussed the findings in Chapter 8 and concluded the thesis in Chapter 9.

Part IV - In this part, I have included all the papers belonging to this thesis.

1.8 How to read the thesis

The thesis is conceptualized as a meta work that reflects on the research project and the findings presented in each of the included papers from the empowerment theory perspective.

- Thus, the thesis can be read on its own from Part I to Part III and if the reader is interested, can continue to read the papers in Part IV.
- Another alternative for reading the thesis is to start reading the Introduction and Chapter 2 and 3 and afterward Chapter 6 and 7. You can then read corresponding papers for each of these chapters. Papers are in Part IV. Only then turn back to Chapter 4, and 5, and thereafter read Part III.

CHAPTER 2

EMPIRICAL SETTING

> "In the attitude of silence, the soul finds the path in a clearer light, and what is elusive and deceptive resolves itself into crystal clearness. Our life is a long and arduous quest after Truth."
>
> *Mahatma Ghandi*

Valuable for understanding my research is a being acquainted with my empirical setting and that is what I present in depth in this chapter. As stated in the introduction, this thesis reports a study of empowering practices for patients in rehabilitation and in the co-design process of cooperative artifacts supporting the empowering practices in rehabilitation. The patient group studied are people with Mild Acquired Cognitive Impairments (MACI), and the rehabilitation process studied is the one of cognitive rehabilitation. I start by presenting what rehabilitation and cognitive rehabilitation are, and what it means to live with MACI.

Then, I describe my empirical setting: the case of cognitive rehabilitation at the Cognitive Rehabilitation Department (CRD) at Sunnaas Rehabilitation Hospital, a hospital specialized in rehabilitation and physical medicine situated in the southeast region of Norway. I introduce the patients and the healthcare practitioners at the CRD, as they were the participants of my study. Then I present an overview of the patient journey in rehabilitation in relation to Sunnaas and a detailed vignette of a patient journey at the CRD. The vignette is overall fictional but each part of it is based on real patients' experience at CDR. I conclude the chapter by presenting some reflections about the vignette and highlighting some of the rehabilitation process's challenges that this thesis later addresses.

2.1 Theoretical Overview

This section provides a general overview of the context and user group that I have studied. I start by presenting what rehabilitation and cognitive rehabilitation are, and I conclude with what it means to live with MACI.

2.1.1 Understanding Rehabilitation

In this thesis, the context being investigated is the one of "rehabilitation". While rehabilitation is a widely used term, different definitions are associated with it in the scientific and political sphere, where countries have adopted their own definition. I initially review the rehabilitation definition and then move into a process perspective of rehabilitation.

"Rehabilitation" etymologically dates back in the late 16th century (earlier (late 15th century) from Medieval Latin "rehabilitat" meaning “restore to former privileges”[1]. It has been used in different contexts such as health (rehabilitate after an illness), individual (restoring someone to her/his privileges after a period of disfavor), or referring to a part of the society (for example, rehabilitating a building or a neighborhood)[2].

In this thesis, I have studied rehabilitation in the healthcare domain. A relevant and widely used definition of rehabilitation in healthcare is the one from the World Health Organization, where rehabilitation is defined as:

> "...a set of interventions needed when a person is experiencing or is likely to experience limitations in everyday functioning due to aging or a health condition, including chronic diseases or disorders, injuries or traumas. Examples of limitations in functioning are difficulties in thinking, seeing, hearing, communicating, moving around, having relationships, or keeping a job" (WHO, 2020).

Hence, rehabilitation aims to help people learn to surpass or manage limitations experienced in daily life due to a sudden change in health. Rehabilitation targets the person’s immediate environment. It does not target major societal changes (Organization et al., 2011).

A special characteristic feature of rehabilitation is that the consequences of diseases concerning function are at the core of the health service. While traditional medical model (as used in Anderson (1995)) is very much centered around diagnoses, functioning is as much important in rehabilitation. A widely used model in rehabilitation is WHO’s International Classification of Functioning (ICF) (WHO, 2011a). According to ICF, a person’s health status can be regarded in several domains, such as body structures and functions, activity and participation, and environmental and personal factors. While traditional medicine focuses on body structures and functions (e.g., respiration, cardiac function, muscle strength, etc.), rehabilitation is as much about activity

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[1] From: https://www.etymonline.com/word/rehabilitation

[2] Merriam Webster dictionary: https://www.merriam-webster.com/dictionary/rehabilitation

and participation. Activity domain stands for activities one is doing with one's body (e.g., walking, writing, eating, showering, etc.).Participation includes activities performed together with others (e.g., taking education, working, caring for others, performing hobbies, etc.). This way of looking at health – especially the focus on the consequences of a health problem rather than mainly its reasons (diagnosis) – constitutes some main principles that have their implications on how rehabilitation work is performed and distinguish it from work in traditional medical models (quote from Paper II, Çarçani et. al., tbd).

Studies have shown that there is clinical evidence that rehabilitation contributes to improving people's functioning in everyday life in different conditions and different rehabilitation settings (Wade, 2020). While improving people's health outcomes in daily life is the main argument for rehabilitation, reducing costs by shortening hospital stays, reducing disability, and improving quality of life is also relevant (WHO, 2011b).

In this thesis, I am interested in the process of rehabilitation, in the way how the care is organized, and what role do patients and healthcare practitioners have in the process. Hence, I present in the next subsection how other researchers have modeled the rehabilitation process.

Process understanding and goal-setting in rehabilitation

Rehabilitation as a process is very individual. It is not possible to have exactly the same process for two different people. This is influenced by the person in need of rehabilitation, the healthcare practitioners involved in that person's rehabilitation, the family members, the society facilities or difficulties, and the resources at hand. However, despite differences, some main activities in rehabilitation are always part of the process.

Wade (2020) has developed a rehabilitation process model based on an extended review of previous models. I have also reviewed previous models (Scotland, 2007; Haskins et al., 2012; Wilson et al., 2009) and referred to them in my previous work (Paper II in Part IV), but Wade's model of the rehabilitation process captures the processes in a more concise way. That is why I present the model in this thesis and reflect on it and discuss it in relation to my findings later in the thesis.

Wade has listed three main processes as part of rehabilitation: process - 1: a general assessment of the patient clinical and life condition, process - 2: definition of rehabilitation goals and a set of interventions and actions to achieve the goals, process - 3: implementation of the interventions in cooperation with a multidisciplinary team of healthcare practitioners. During the implementation, there is also a need for further assessments if the interventions helped achieve the goals. If they are not helping to achieve the goals, refinements need to be done. If the goals have been achieved, new goals can emerge, or the rehabilitation process finishes. The model is shown in Figure 2.1

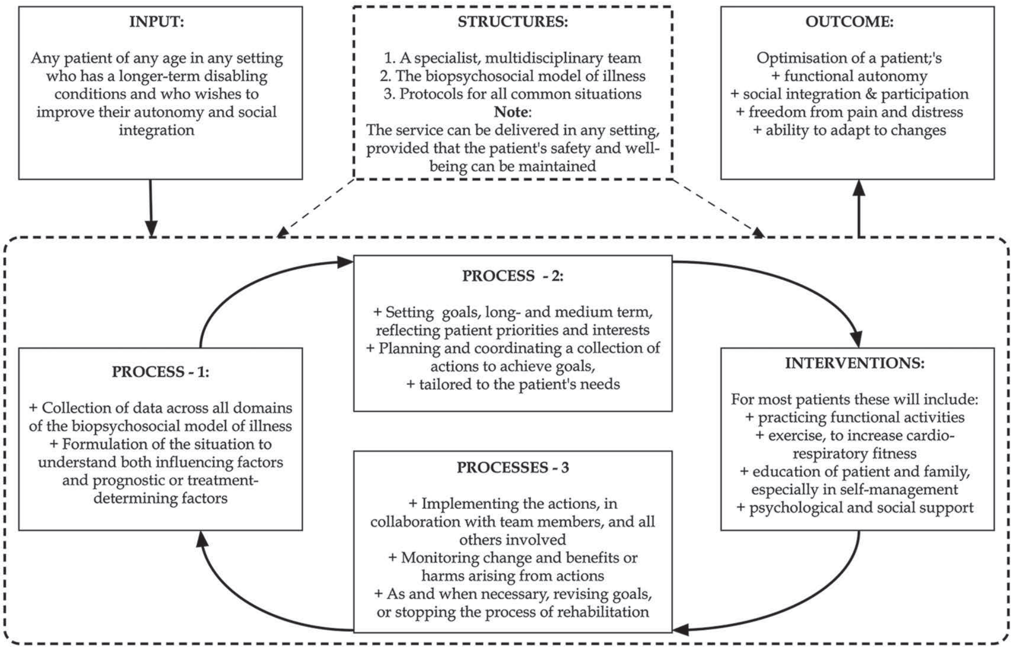

Figure 2.1: Rehabilitation model by Wade (2020, p.580)

Wade (2020) highlights the healthcare practitioners’ team’s multidisciplinarity as one of the main characteristics of the rehabilitation care model. Wade (2020, p. 574) states that "a team is not just a collection of people who happen to be working with a specific patient; a team works together with each other over time and with many patients". The process in every step sees the patient collaborating closely with the multidisciplinary team and with the patient’s keen (Wilson, 2002; Wilson et al., 2009; Levack et al., 2015).

Two other characteristics of effective rehabilitation stated by Wade (2020) are: the existence of structured protocols for the services and developing person-centered (and family-centered) rehabilitation services. He discusses how rehabilitation has similarities with the person-centered care model, and they have been discussed in conjunction with one another.

While Wade’s model provides a good overview of the rehabilitation activities, it is still on a meta-level, and there is no clear description of how the patients and the multidisciplinary team should interact with each other within these three meta processes. Moreover, the model is very clinicians oriented, and while the position of patients is set as central in the processes, it is not problematized, questioned, or discussed in terms of the possibility for further empowerment.

Another relevant part of the model is developing a rehabilitation plan (Evans, 2012; Wilson et al., 2002). I will initially present what rehabilitation goal-setting that leads to a rehabilitation plan means.

Defining rehabilitation goals and interventions

Goal-setting is considered part of best practice in rehabilitation. However, it was largely ignored or unknown in the academic rehabilitation literature until the late 1960s. An early and influential reference to a structured approach for goal setting was a paper by Kiresuk and Sherman (1968). During the 1970s, there was a growing concern regarding the participation of patients in clinical decision-making. The patient participation in goal-setting was linked to ethical obligations such as working towards outcomes individually meaningful and valued by patients (Trieschmann, 1974). This implied regular discussion with patients about their progress towards individualized goals. From the 1980s onward, goal setting or goal planning started becoming an increasingly common rehabilitation program component.

Goal-setting is defined broadly as a process in which the patient and members of a multidisciplinary team, compounded by a set of healthcare professionals such as a doctor, nurse, Physical Therapist (PT), Occupational Therapist (OT), psychologist, etc., agree on a set of rehabilitation goals to be achieved during a rehabilitation program (Wade, 2009). Rehabilitation goal-setting is not only an administrative tool but is considered a clinical intervention in rehabilitation (Siegert and Levack, 2014).

In this study, I apply the "rehabilitation goals" definition by Levack et al. (2015, p. 9) who state that rehabilitation goals are:

> "A desired future state to be achieved by a person with a disability as a result of rehabilitation activities. Rehabilitation goals are actively selected, intentionally created, have a purpose, and are shared (where possible) by the people participating in the activities and interventions designed to address the consequence of acquired disability."

Hence, first, a goal is an intended future state. This will usually involve a change from the current situation, or in some circumstances maintaining a current state in the face of expected deterioration might also be a goal. Second, and of equal importance, a goal refers to the intended consequence of the rehabilitation team's actions. A goal is not, nor should be, a simple prediction of what will happen. It should be the intended result of some intervention(s) argues Evans (2012).

Although professionals and teams will always have some reason for their actions in every healthcare setting, the goals are often unstated and unconsidered in a particular situation. In rehabilitation, the goal-setting process as Wade (2009) argues ensures explicit identification of the reasons for all activity. This explicit definition of the reasons for all activities becomes the core of the work process in rehabilitation.

Moreover, in contrast to acute wards, the rehabilitation goals are explicitly stated in terms of everyday life activities aiming to motivate behavioral change and engagement of the patients in rehabilitation (Wilson et al., 2009). This differs from traditional medicine, where the main drive is improving the patient's clinical condition(s) related to the specific illness.

Rehabilitation goals are closely related to the interventions that the patient and the multidisciplinary team will work on as a way to achieve the goals. An intervention is defined as "an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning, or health conditions" (WHO, 2018). Interventions in rehabilitation can variate. Wade (2020) argues that the most common interventions found in rehabilitation are exercise, education, the giving of information, and providing psychosocial support. Additional interventions can be prevalent in specific rehabilitation programs.

Different rehabilitation programs are offered for people with different clinical conditions. For example: rehabilitation for stroke patients, rehabilitation for traumatic brain injury, rehabilitation for cardiac disease, rehabilitation for respiratory problems, etc. Also, rehabilitation programs can be targeting specific disabilities in functionality, such as physical rehabilitation or cognitive rehabilitation. The literature presented in this subsection is relevant across rehabilitation processes.

In this thesis, as my case study, I have gone in-depth into the cognitive rehabilitation process. Cognitive rehabilitation helped me in investigating rehabilitation practices for patient empowerment in rehabilitation. In the next subsection, I elaborate on cognitive rehabilitation and the specific characteristics and people that can benefit from such a rehabilitation program.

2.1.2 Cognitive Rehabilitation

Cognitive Rehabilitation is a specific rehabilitation program defined as:

> "a process whereby people with brain injury work together with health service professionals and others to remediate or alleviate cognitive deficits arising from a neurological insult." (Wilson et al., 2002, p. 99)

Cognitive rehabilitation is offered to those people that have had an Acquired Brain Injury (ABI) and have as a consequence some form of mild to moderate cognitive impairments (Haskins et al., 2012).

Acquired Brain Injury (ABI) refers to any brain damage that happened after birth. ABI is an umbrella term that includes Traumatic Brain Injury (TBI) and non-Traumatic Brain Injuries (non-TBI). TBIs are those cases in which the damage caused to the brain comes from an external force such as a blow, bump, or jolt to the head. Examples are cases of accidents, falls, or assaults. Instead, non-TBIs are those injuries to the brain that are not caused by an external physical force to the head. Examples are stroke, brain cancer, aneurysm, etc.

ABI is an alteration of neuronal activity that compromises the physical integrity or function of one or more areas of the brain. Impairments resulting from an ABI often affect cognitive function, as well as language, memory, attention, and information processing faculties, leading to partial or total disability that is likely to prevent people's functional and psychosocial recovery even in the long term (Giustini et al., 2013).

After an ABI, the level of cognitive impairments can be mild, moderate, or severe (Eghdam et al., 2012). ABI is referred to as the "silent epidemic" because impairments are often undetectable, and its incidence is often underestimated.

Rehabilitation after an ABI has proven to be effective and is highly recommended. Cognitive rehabilitation is recommended for cases with a mild and moderate level of ABI symptoms (Rees et al., 2007). It facilitates retraining in the ability to think, use judgment, and make decisions. In the Manual of Cognitive Rehabilitation (Haskins et al., 2012), widely used in clinical settings where specialized rehabilitation is offered, it is stated that cognitive rehabilitation influences correcting memory deficits, concentration and attention, perception, learning, planning, sequencing, and judgment.

Cognitive rehabilitation also relies on the goal-setting process. It aims to ameliorate the injury-related deficits, maximize safety, daily functioning, independence, and quality of life. There are two different cognitive rehabilitation approaches, the more impairment-oriented such as the Manual of Cognitive Rehabilitation (Haskins et al., 2012) and a more holistic one focused on the everyday life aspects of the person in need of rehabilitation. This is based on Barbara Willson and colleagues' work in the Oliver Zangwill Center (Wilson et al., 2009).

Haskins et al. (2012) have described cognitive rehabilitationas divided into two parts such as 1) assessment and planning and 2) implementing the treatment plan. The assessment and planning are related to the activities for defining rehabilitation goals and planning the interventions. The implementation of rehabilitation interventions goes in three stages: a) acquisition - related to the learning process of the patient regarding rehabilitation and themselves and their condition, b) application - start trying out strategies and learning them with the aim of internalization, c) adaption - transfer of knowledge acquired into new tasks and environment such as home and own community.

Instead, Wilson et al. (2009) describe a holistic approach to Neuropsychological Rehabilitation by emphasizing people's lives and the environment as a strong influence in the need for rehabilitation and how the impairments influence not only the cognitive but also the physical, emotional, and functional state of a person. They also describe the relevance of the goal-setting approach. They describe the goal-setting process as a process where the patient, family members, and the multidisciplinary team are involved in negotiations. The goals should be measured because patients can see more clearly changes and be motivated in this way.

Cognitive rehabilitation is not only one of the case studies that I could have chosen but also a best practice when it comes to the techniques used to promote patient involvement in the rehabilitation process. This creates grounds for modeling patient empowerment in rehabilitation.

2.1.3 People leaving with Mild Acquired Cognitive Impairments (MACI)

In this thesis, I have in focus those people that have had a mild ABI and now have to live with the challenges that the decrease in cognitive abilities brings to them and their families. Different terms have been used in the literature for such a group, such as mTBI (mildTBI) (McInnes et al., 2017), mABI (mildABI) (Pedro, 2015), or MCI (mild cognitive impairments) (Luis et al., 2003). I was initially in doubt regarding the terminology that would better represent the people I was working with until I encountered the term Mild Acquired Cognitive Impairment(s) (MACI) coined by Eghdam et al. (2012, p. 1) and used "to describe a subgroup of patients with mild cognitive impairment(s) (MCI) who are expected to reach a stable cognitive level over time. This patient group is generally young and have acquired MCI from a head injury or mild stroke". I have adapted the MACI definition to refer to:

> "adult people with mild cognitive impairments due to ABI, who have passed the acute phase of their ABI and are in need of rehabilitation as a possibility to improve or compensate their function in everyday life. These people are able to participate in an active rehabilitation program including both individual and group treatment sessions."

People with MACI may face difficulties in performing everyday tasks, fulfill previous roles, and maintain personal-social relationships (Krogstad, 2011; Nilsson et al., 2011; Toglia, 2005; Prigatano, 1999). They also can experience difficulties in cognitive and emotional processing while having no or limited movement disorders and being independent in self-care (Carlsson et al., 2009; Nilsson et al., 2011).

Some of the common symptoms can be:

- Experiencing a lack of energy in doing tasks and increase in the time needed to do even simple tasks.
- Experiencing challenges to remember and learn new things due to memory deficits.
- Experiencing attention problems and trouble concentrating on the most important things.
- Experiencing a reduced ability to multitask and becoming very tired when multitasking is needed.
- Experiencing an increase in response time due to a slower process of thinking.
- Experiencing lack of motivation and thus difficulty in initiating things.
- Experiencing difficulties to switch topics.

- Experiencing difficulties in stopping, which relates to impulsivity, overactivity, and difficulties in controlling unwanted or inappropriate responses.
- Experiencing a reduced understanding of oneself, which involves a reduced ability to perceive one's own mistakes, to take into account the impression one makes on others, or to assess a social situation accurately.
- Experiencing thinking specifically and taking everything literally. This can also be associated with a loss of the ability to plan, look ahead, and think purposefully.
- Experiencing difficulties with using language and communicating, such as not finding a word, repeating the self in a conversation, having difficulties in making a point in a conversation, mixing words, or having difficulties in understanding humor or irony.
- Experiencing difficulties in processing the information received, solving problems, and executive functioning.
- Experiencing changes in how they engage in social life and social communication.

The list presented above is a translated and adapted summary from Sunnaas (2011b) and Sunnaas (2011a).

I have tried to capture the most encountered challenges, but the list can continue. Each MACI person can have a combination of the above symptoms. Thus, it is understandable that the group is very heterogeneous and also very difficult to spot. That is why it is not unusual that MACI patients can go years without treatment until they are properly diagnosed. In one of my interviews with a patient, she told me: *"I didn't know why I was feeling so tired all the time. Now I know, and I can do something about it, and my family knows as well"*.

In MACI people, these symptoms are mild, and the person in most cases continues having an active life, working or participating in social activities, running a house, or following hobbies. However, their life is not the same (Ruff et al., 2009).

In this thesis, I used interchangeably different variations to refer to people living with MACIs, such as "people with MACIs, MACI people, or MACI person". I use "patient(s) with MACIs, or MACI patient(s)" to refer to people with MACIs who are patients in a rehabilitation institution, which is the setting of my study. Moreover, in some cases, I use the term patient(s) even when referring to the home context because people with MACI have a chronic disease, making them chronic patients in a rehabilitation context. Instead, I use the terms "people with MACI, MACI people, or MACI person" when referring to them in regard to the co-design process.

2.2 The case of Cognitive Rehabilitation at Sunnaas Rehabilitation Hospital

The study presented in this thesis was conducted in Norway, in a specialist institution called Sunnaas Rehabilitation Hospital, in the Cognitive Rehabilitation Department (CRD) of the hospital where MACI patients are admitted.

An overview of Norwegian rehabilitation legislation

Norway has a very well-organized healthcare system, with a lot of services offered to the people living in the country. Huge advancements and a big focus and funds have been allocated to rehabilitation services. The right to receive rehabilitation services is instated in the law and regulations.

Rehabilitation in Norway is offered in two rehabilitation settings: at specialist institutions or in municipalities (Helsedirektoratet, 2020). The municipalities have the overall responsibility for the follow-up and should refer the person to a specialist institution when there is a need for more specialized services than what the municipality can offer.

The Norwegian Health Directorate (Helsedirektoratet, 2020) defines rehabilitation as:

> "Habilitation and rehabilitation should be based on the individual patient’s and user’s life situation and goals. Habilitation and rehabilitation are targeted collaborative processes in different arenas between patients, users, relatives, and service providers. The processes are characterized by coordinated, coherent, and knowledge-based measures.
>
> The purpose is that the individual patient and user who is at risk of having physical, psychological, cognitive, or social disabilities should be given the opportunity to achieve the best possible ability to work and exercise independence, and participation in education and working life, socially and in society."

The definition, in this case, is a directive, and the rehabilitation settings in Norway should translate the definition into concrete actions and organization of services. The above definition can be broken down into some main points to be taken into consideration: 1) Rehabilitation is meant to reduce the impact of a broad range of health conditions in people’s daily life, 2) It should continue for a certain period of time until the person has achieved a satisfying functioning level, 3) This can involve different rehabilitation settings, 4) It should be a "collaborative process" between patients, users, relatives, and healthcare service providers, and 5) The aim of rehabilitation is to support patients ability to work and exercise independence, and participation in education and working life, socially and in society. Hence, the word rehabilitation in itself depicts a process that has the above-listed characteristics.

To ensure the coordination of services when there is more than one healthcare setting that the patient will have to deal with, the government has introduced the "Individual Plan" (IP) (Helsedirektoratet, 2018). In the legislation, it is stated (as translated by Norwegian Health Directorate (Helsedirektoratet, 2018)) that "An individual plan can be described both as a tool, in the form of a planning document, and a structured collaboration process. The plan must be updated continuously and be a dynamic tool in the coordination and targeting of the service offer". A special unit called the coordination unit has been established and has the responsibility for coordinating and facilitating services for the patient. However, the unit is activated when they receive a request for an individual plan from any of the actors that can be part of the plan.

Hence, coordination between the rehabilitation settings is deemed highly relevant in the legislation, and practically structures have been created to facilitate a person's rehabilitation in the best way.

Another statement in the law relevant to bring up in this thesis is regarding the patient's position in rehabilitation. The law states (translated from Norwegian):

> "The municipality and the regional health authority shall ensure that the individual patient and user can participate in the implementation of their own habilitation and rehabilitation services, cf. the Patient and User Rights Act § 3-1. By implementation is meant planning, design, exercise and evaluation. The municipality and the regional health authority should facilitate the participation of patient and user representatives in the planning, development and evaluation of the rehabilitation/habilitation activities."

This means that the rehabilitation settings have a responsibility to facilitate patients' or their representatives' involvement in every aspect of rehabilitation. This overview of the Norwegian rehabilitation services environment is relevant for making sense of the rehabilitation practices. I have studied the organization of rehabilitation in Norway in one specific specialized institution, Sunnaas Rehabilitation Hospital, on which I elaborate more in the next subsection.

Sunnaas Rehabilitation Hospital

Sunnaas[3] is Norway's largest specialist hospital in the field of physical medicine and rehabilitation. It operates on a national and regional level providing multidisciplinary rehabilitation to people with complex functional impairments following illness or injury. It is also one of the biggest institutions of specialized rehabilitation in Europe. Their philosophy is to always provide the best services for their patients and support the patients through therapies and training to achieve the highest possible level of functioning in everyday life and participation in activities. This by taking into consideration contextual factors that can influence a patient's condition. The three pillars of the hospital are

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[3] Sunnaas rehabilitation hospital - a way forward - https://www.sunnaas.no/Documents/Brosjyrer/Sunnaas_Rehabilitation_Hospital_a_way_forward.pdf

clinical treatment, research, and collaboration. Sunnaas serves as a coordination hub for rehabilitation in the region and contributes to developing rehabilitation practices due to continuous research.

The work organization at Sunnaas is considered a best practice for specialized rehabilitation in Norway and abroad. Sunnaas is positioned in the South East region of Norway and welcomes patients from different counties in this area. Other institutions provide the same services as Sunnaas in other regions. However, Sunnaas is the biggest one in Norway, and sometimes patients from other regions in need of some specific rehabilitation therapies come to the hospital.

Different rehabilitation programs are offered at the hospital. I studied in depth the cognitive rehabilitation process, which I present in the following subsection.

Cognitive Rehabilitation Department (CRD)

Cognitive Rehabilitation at Sunnaas is provided at the Cognitive Rehabilitation Department[4] (CRD). The CRD was established as a project in the '90s, and the focus was to serve patients with predominantly cognitive impairments of a mild to moderate degree where an intensive and adapted rehabilitation program was offered (Becker et al., 2014). However, in 2005 it was finally established as a unit, becoming Norway's first permanent unit for cognitive rehabilitation for ABI – offering individual and group-based rehabilitation services.

The department has a capacity of 20 in-bed rehabilitation patients. It has a staff of 23 employees and offers a standardized 5-week rehabilitation program with a 1-week follow-up after 2-6 months. Patients admitted at the department have minor or no physical/motor impairments, but mainly cognitive impairments such as memory, attention, executive functioning, language, and fatigue. Every week there are approximately 3 new primary stay patients and 4 follow-up patients coming at the department.

To study empowerment in rehabilitation and co-design, both patients and staff from the department participated in the study. I describe each of them below and then present a vignette of a patient's journey during rehabilitation at CRD.

2.2.1 Who are the patients?

Patients admitted at the CRD are adults with mild to moderate cognitive impairments due to ABI. They typically have cognitive impairments caused by Cerebrovascular Accidents (CVA), TBI, anoxic brain injury, brain tumors, and infectious brain diseases. Their ABI is verified through typical medical procedures (Becker et al., 2014). Another characteristic taken into consideration for admission is the person's need for such a rehabilitation program.

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[4] more information at: https://www.sunnaas.no/avdelinger/klinikk/avdeling-for-kognitiv-rehabilitering#les-mer-om-avdeling-for-kognitiv-rehabilitering

The program includes both individual and group treatment sessions, and communication is relevant, so the people admitted in the program should not have moderate to severe aphasia or moderate to severe motor deficits. Patients that have such problems are served by the hospital's stroke or TBI departments.

Patients at the CRD are able to maintain an independent living and aim to return to an active social life and work. Many patients who live in the vicinity spend the weekend home as a strategy to facilitate generalization of treatment efforts to daily living also during the admission period.

Patients coming at the CRD are mostly people that do not come straight from acute hospitals. Usually, they have experienced being home and trying to live with the impairments in everyday life. It is not unusual that cognitive impairment remains undiagnosed for a longer period and that patients are referred to the CRD several years after ABI.

In order to draw a picture of the CRD patients that were involved as participants in my study, I will present my encounters with one patient and the experience I had.

Meet Olav

This is the case of a patient who I will call "Olav". Olav is a man in his 50s who a few years back had a stroke.

I met him during one of my workshops at the beginning of the study, where we discussed the layout design of the goal plan document, a paper document that patients used at the hospital. In the workshop were involved 4 patients. Olav was active during the workshop and shared interesting ideas with others. *"He is an artist."* - said another participant in the workshop. I learned during the workshop that he used to work a lot before. Now he felt tired easily, so he had to change his working habits. However, during the workshop, he was quite engaged and was involved in all the discussions.

After the workshop, I didn't see him again until when I was conducting my observations at the hospital, shadowing one of the PTs. After six months of being home, he had returned to the hospital to have a follow-up week of rehabilitation. When I saw him in the corridor, I recognized him immediately. I noticed that he was looking at me as well. However, it took him a while to remember who I was, and he said..*"ah the workshop"*.

During that time, we were testing a new design of the goal plan document used at the hospital, which had come out as a result of those workshops he contributed into. Thus, with one of the Occupational Therapist (OT) at CRD, we decided to ask him if he would like to receive a diary with questions regarding the new design of the goal plan and have an informal interview with me afterward to discuss the new design. Olav's nurse responsible for that follow-up week was the one that asked him if he wanted to be involved in this evaluation of the document design that we were doing. The nurse told me that he accepted and was enthusiastic about it.

Later that day, the nurse gave Olav the document where he had to write impressions on the new goal plan. He was sitting with this document in the

CRD lobby and writing something on it. I passed by the lobby to go to another observation meeting, and I greeted him. He pulled the document up and showed it to me as a way to tell me that he was working on it, and smiled. I wrote this moment right away in my observation notes.

The next day I had the interview scheduled with Olav. I went early to the hospital because I had observation sessions scheduled. When I arrived, Olav's nurse approached me and told me that Olav felt very tired that morning and he could not meet me. Moreover, he didn't remember where he had put the document he was working on yesterday when I saw him, and he was feeling bad and frustrated. So she told me that it was not possible to continue with the meeting, as Olav needed to be alone to regain energies. That was his last day of follow-up at the hospital, so I did not have the possibility to meet him again.

Olav is one of the cases at the CRD that suffered from memory problems and fatigue after the stroke. His story shows how the MACI patients, part of our society, our workplace, and our families, try hard to keep up with things and want to have the same engagement as before. However, they have challenges that, on a superficial look, we can easily forget about.

2.2.2 Who is involved in the multidisciplinary team?

At the CRD, the patient works together with a multidisciplinary team that is compounded by the following healthcare practitioners. This is a description adopted from Sunnaas (2017) with some additional material based on my acquired knowledge for each of the multidisciplinary team roles.

- Medical doctor - The department has a senior doctor specialized in physical medicine and rehabilitation who is medically responsible for the patient's rehabilitation process. It works closely with the team coordinator and others in the team to make sure the patient receives adequate treatment. The medical doctor is responsible for the clinical condition of the patient and for the medicines.

- Team coordinator - It has a relevant role in coordinating patient's rehabilitation before coming to the hospital, during the stay, and after discharge. It contributes to ensure continuity in the patient's course of treatment, personal plan, and cooperation with local health services. Moreover, the team coordinator assures that the whole team is coordinating as needed to provide the patient with the defined interventions.

- Nurse - Every patient has an assigned nurse that follows the patient throughout the stay. The nurse takes care of the patient's basic needs. At the CRD, the nurses are specialized to work with patients with cognitive problems, and they support the patients in reflecting and formulating rehabilitation goals. In collaboration with other multidisciplinary team members, they organize and arrange ways in which the patient can master everyday tasks to the best of her/his ability. The nurse also contacts family members before the patient comes to the hospital and also during the stay.

- Physical Therapist (PT) - Each patient is also assigned a PT. The PT treats, trains, and advises to improve the patient's physical function to be as independent as possible and master everyday life.
- Occupational Therapist (OT) - The OT has a very important role in rehabilitation. Supports the patient in daily living activities by advising on training and technical assistive aids to perform these activities. OT's aim is that the patient becomes as active and independent as possible at home, work, school, and recreation. During my observations at the CRD, I noticed that OTs had a very central role in patient's rehabilitation, always with a toolkit of helpful techniques and tools to apply to suggest to the patient.
- Psychologist - The psychologist at the CRD supports the patients with psychological aspects related to changes in life, permanent injuries, and illnesses. S/he conducts a neuropsychological assessment and gives counsel for psychological issues. Psychological help after an injury or illness is very relevant as people need to accept the new situation and find the motivation to be engaged in rehabilitation.
- Social worker - The social worker gives advice and information regarding rights and welfare arrangements connected with work, home and health, and can assist the patient to get in touch with other agencies of help if necessary. The social worker contributes also with support for economical rights.
- Speech and language therapist - Provide therapy to patients that have speech and language problems related to mild aphasia. S/he has competences in: language and communication, visual impairment, swallowing impairment (dysphagia), computer-based assistive aids, educational and vocational counseling.
- Patient consultant - These are previous patients who can be role models for the patient and advise the patient and the patient's family on how to cope with the new situation. It contributes to bring the patient perspective into the multidisciplinary team.

During the study at the department, I had the opportunity to know, talk and discuss things with representatives from each of the roles. The general interest in improving the services for the patients and the concern toward the patients' well-being was very fascinating.

2.2.3 An overview of the cognitive rehabilitation patient journey

The patient journey with Sunnaas Rehabilitation Hospital starts with a meeting between the person and maybe her/his family members and the medical doctor and psychologist from the CRD at the Sunnaas outpatient clinic[5]. This outpatient clinic serves as a diagnostic center for patients that need initial assessment to evaluate if they qualify for specialized rehabilitation. Moreover, in the clinic, group therapies are offered for patients who have already been at the hospital and still need group therapy after discharge. The patient meets at the clinic with the medical doctor and the psychologist, who assess the patient's condition and decide if there is a need for inpatient rehabilitation at the hospital or not. If the patient is admitted, s/he has to wait for her/his assigned date to be hospitalized. Some more activities are organized at the clinic to prepare the patient before the arrival at Sunnaas, such as a hospital presentation and an introduction on how to define rehabilitation goals. In these encounters with the patients, they are given some printed documents with information, a copy of the goal plan document, and a document to start filling up before coming to the hospital where the patient should write about her/his daily life challenges.

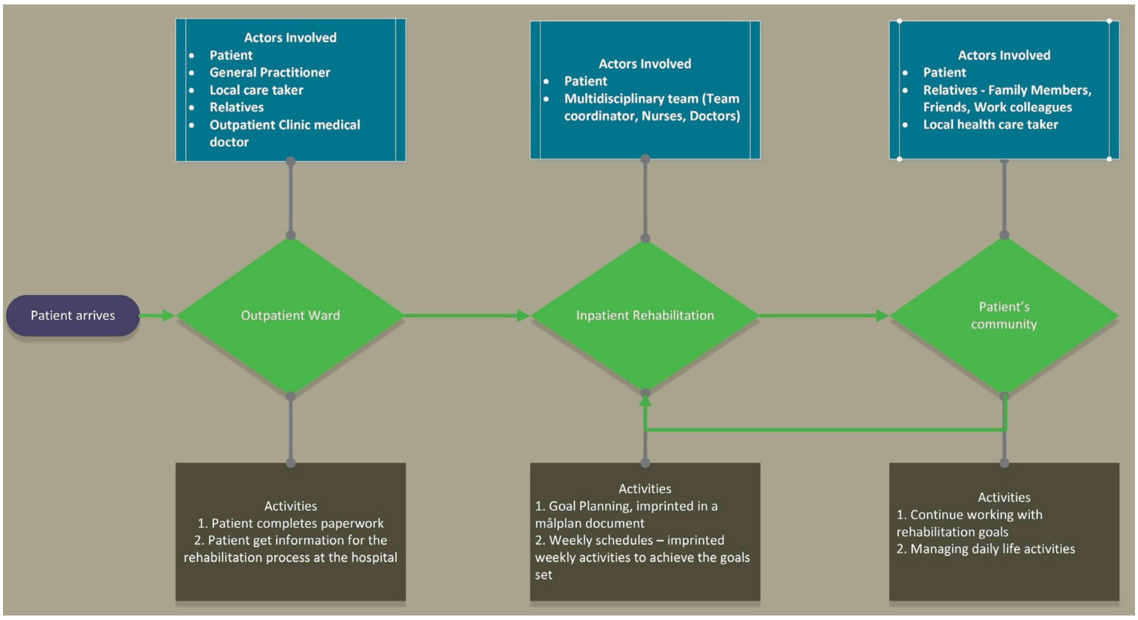

Figure 2.2: Patient journey in cognitive rehabilitation from the moments it gets in contact with Sunnaas's outpatient clinique

The patient is recommended for an assessment at the outpatient clinic by the General Practitioner (GP) - a doctor assigned from the municipality in Norway for every inhabitant. The GP does the initial screening of the patient's needs and, when there is a need for specialized consultation or assessment,

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[5] More info here: https://www.sunnaas.no/avdelinger/klinikk/avdeling-for-poliklinikk-inntak-og-ambulant-tjeneste/helse-og-arbeid-poliklinikk-aker

recommends the patient to a specialist. If the GP assesses that the patient needs more specialized rehabilitation, s/he books a meeting for the patient at the outpatient clinic of a specialized rehabilitation institution.

The moment the person is hospitalized s/he spends five weeks at the CRD. During this period, the patient is introduced to her/his multidisciplinary team that works together with the patients initially in assessment, defining rehabilitation goals, and deciding on some suitable interventions. The rehabilitation goals and the interventions make the rehabilitation plan, which at CRD is imprinted in what is called the goal plan document. Once the goal plan is established, the patient starts the rehabilitation interventions. Every activity that the patient does is related to one or many of the interventions. Activities and interventions are individual or group-based. Every week the patient receives a printed weekly calendar that includes all the activities for the week. This calendar for the clinicians is an MS Word document. This goes on for four weeks until discharge.

Before discharge, the multidisciplinary team with the patient make a plan for the patient rehabilitation at home, and the multidisciplinary team writes a report for the rehabilitation services received and recommendation for further rehabilitation activities at home. The report is made available to the GP, local rehabilitation therapists, or the coordination unit, which support the patient with the rehabilitation in the municipality of residence. In the next section, I present a vignette of a patient journey at the CRD and enter more in details on the rehabilitation in the department.

After two or six months at home and in her/his community, the patient returns to Sunnaas for one follow-up week at the CRD. This week serves to assess how the patient is doing and if changes in rehabilitation are needed or not. Some patients during the six months could have participated in individual or group activities happening at the Sunnaas outpatient clinic with staff from the CRD. Based on the patient's condition after the follow-up at the hospital, the rehabilitation process may comprise community-based rehabilitation, relevant follow-up programs at Sunnaas, or outpatient clinic follow-up. The rehabilitation process continuity will relate to the changes in the patient's clinical condition. If the patient can manage his daily life effectively, then the rehabilitation period is considered finished.

What was presented above is summarized in the graph in Figure 2.2 highlighting the settings in the middle row, the people involved in the rehabilitation process in the top row, and the activities in the bottom row. The journey is not linear, and it can have as a start any of the rehabilitation settings shown in the figure.

2.2.4 A patient journey vignette: Maria at the Cognitive Rehabilitation Department

In order to present the dynamics of interactions during cognitive rehabilitation at the CRD, I have created a vignette. The vignette is based on a persona (Pruitt and Grudin, 2003) that I used during one of my workshops.

The whole vignette is related to a fictional character, but each part of it is built on pieces of notes that I took during my observations at the CRD or findings from the co-design workshops with patients and healthcare practitioners. In my observations, I did not follow a single patient journey from the start till the end, so I used my notes from different patients that I met during my observations and put them together to create a vignette of a patient journey at the CRD. The vignette is long as it tries to provide a rich description of the interactions. The vignette is made up of some parts representing specific moments or meetings during rehabilitation (included in boxes). The other parts represent summaries of activities or additional information on the persona's feelings regarding the activities. I learned more about the feelings and opinions during co-design workshops with the patients.

> "Maria, 43 years old, highly educated, worked as a consultant at a directorate until the injury. She is married and has two kids. She experiences a lack of energy (fatigue), problems with planning daily life, and getting things done. Has a lot of half-done tasks/projects at home. She has noticed problems with attention but is not fully aware of why she experiences attention problems. She tries to manage daily life as she used to, and she doesn't tell many around her about her struggles, trying to cover up her difficulties. She is starting to get more insight, but her husband reports more problems in terms of memory, attention, and fatigue than she reports herself. She had a meeting with the medical doctor at Sunnaas outpatient clinic and was accepted from a period of cognitive rehabilitation at the hospital."

Maria's welcoming at CRD

Maria came to the hospital around 12:00. The first staff member she met within the department was the nurse. The nurse had already prepared Maria's file and printed it out. After the welcoming greetings, the nurse showed her the way to the room. The whole department, offices, and patients' rooms are on the same floor, so walking is short. Before Maria arrived, the nurse double-checked the whiteboard in the nurse room, which shows the information on the room numbers in which new patients are coming - IN or others leaving - OUT. The patient details are in the hospital's Electronic Medical Record (EMR) system called DIPS (Distribuert Informasjons og Pasientdatasystem i Sykehus), and no patient information lies on the whiteboard. Each room has its own assigned nurse, which belongs to one of the two teams in the department. Each of the teams has a whiteboard schedule with each of the healthcare practitioners that will be involved with the patient in a specific room. This list is dynamic, depending on the patient's needs and the availability of the staff. A team tries to coordinate resources within the team and when it is needed across the two teams.

Maria was accompanied by her husband. The nurse brought them to the room, and they discussed having a meeting later with the medical doctor and the nurse. The meeting had already been registered in a paper document called the weekly plan that the nurse gave to Maria once they entered the room. The document is a calendar of the activities that Maria would do during the week and some general activities organized at the department or hospital level where she could participate. The nurse told Maria that she would receive such a calendar for every week at the hospital.

Meeting the medical doctor

Later that day, Maria and her husband meet the medical doctor and the nurse. The meeting started by discussing Maria's condition. While Maria described her condition, the husband also emphasized some parts that Maria thought she was doing fine. She said that sometimes she forgets things. For the husband, this happened often and was very relevant to address. Her husband's intervention showed the Maria has a lack of awareness of her situation. However, she added that her family should understand her, and the husband admitted that he needed help to understand her and the new situation she was in after the stroke. Meanwhile, the doctor mapped Maria's medicine and meanwhile assessed her in this meeting.

Maria met with her OT, her PT, and the psychologist in separate meetings in the upcoming days. They were mostly assessment meetings where each of the healthcare practitioners assessed Maria's situation and learned more about her and her life before and after the illness, the social and environmental situation in her life, her patient journey till that moment and the expectations from rehabilitation. For Maria, these were mainly talks to tell about herself, and she did not understand how useful they could be.

Assessment meeting

When she met with the OT, Maria told her how tired she felt all the time. She said that she used her phone and notebook to keep track of things she had to do, meetings, and activities. She said that she had a bad memory, so she had to have things written somewhere. She looked at the notebook every morning and then continued with her day. The OT asked her also about her phone usage. She said that she used the notebook in general for long-time activities, and the small things that she wanted to remember throughout the day she wrote down on the phone as notes to herself. For example, she wrote down what to shop for if she was going to do groceries. At the end of the meeting, the OT summarised what they talked about and asked Maria if she had thought about possible rehabilitation goals before coming to the hospital. Maria said that she had seen the goal plan document, but she had not filled up anything.

However, she said to the OT that she wanted to learn strategies on how to present her condition to others. She also highlighted that it was challenging to deal with everything at work, and work for her would become quickly overwhelming, and she would feel left without energy. She added that it took more time now to do things, and sometimes she got irritated and stressed with herself, like "why I got this". So, she wanted to be able to manage herself better in relation to her work.

That was a good session for the OT, as she could assess Maria based on the list of things highlighted in the OT practice for assessment and explored more about her life, biography, and how the injury had changed that. This is relevant for the OT to consider and suggest interventions that are specific to Maria.

In the next few days, Maria continued socializing with the other patients and participated in some group activities that are offered for every patient at the unit, such as morning walk, where one of the team members brings all the patients that want to join in a walk around the hospital areas. The hospital is positioned on a peninsula with a spectacular view. Maria enjoyed the walk a lot. Moreover, she participated in cycling, mindfulness, and some educational group therapies (such as theme café and cognitive group, in which she learned more about her condition and ways to cope with it), or relaxed in her room.

Almost at the end of the first week at the hospital, she met again with the nurse and OT to discuss possible rehabilitation goals.

Discussing rehabilitation goals

Formulating goals was not easy for Maria. Thus, the nurse and the OT, based on the previous meetings with her, tried to help her reflect which aspects of her life affected by the impairments had priority and she wanted to work on during the next four weeks of rehabilitation at the CRD. Again, Maria stated how much she wanted to not feel so tired and find ways not to feel stressed and irritated if something was not working. Considering her husband's concerns in the first meeting, she was asked if she preferred her family to get more information about her condition and how they could cope with it together, and she agreed. The nurse and the OT interpreted Maria's will to be less stressed as her "learning how much cognitive and physical activity she can withstand and learn how to manage things with her capacity limitations". They also talked with Maria about possible therapeutic options and asked for her opinion on what could be most suitable for her considering her goals and life situation and previous experience on rehabilitation techniques. The nurse asked if she would be willing to have some exercises at home, such as logging activities, keeping a plan for activities, etc. This is relevant for the CRD as they want their patients to try out exercises at home while they are still at the hospital, so the healthcare practitioners can assist the patient to learn rehabilitation techniques.

The nurse and the OT left the meeting with some ideas about Maria's goals as the interpretation mentioned in the textbox, and they went to write the goal plan document in DIPS, regarding goals and interventions they reflected to be suitable and were previously discussed with Maria. Maria did not have access to the document, so she couldn't actually write her goals. Moreover, this was difficult for her. She had had the printed goal plan template at home before the hospital, but she was unsure what to include there. After the OT and the nurse started the goal plan document, the other staff members added on the goal plan document those kinds of goals and interventions that they have discussed with Maria and were specifically related to them. For example, the PT adds activities regarding assessment and training of the physical condition.

Finalizing the rehabilitation plan

At the end of the first week, Maria and her husband participated in the goal plan meeting, where the patient and the multidisciplinary team agree on the final version of the goal plan. The meeting started with the multidisciplinary team meeting first with each other to go through the goals, check for consistency and discuss their assessment and biography of Maria throughout the week. While they have a shared view of the document in the EMR of the hospital, the system is very basic, and it does not offer possibilities for different ways of interaction between the team in writing the goals. Instead, the patient does not have access at all. So the meetings are the only possibility to commonly work on the goal plan.

After 20 min, Maria and her husband joined. The goal plan was displayed on a screen at the meeting room. Maria and her husband agreed with the goals, sub-goals, and interventions, but they wanted a stronger emphasis on the possibility to increase the capacity to get back to work, and they wanted that to be represented in the goal plan. The OT made a change in one of the goals to include this specific requirement. The OT stated that the interventions planned also cover this part, so there is no need to change the interventions. The team members who had added different interventions explained to Maria and her husband the reasoning behind the interventions. In the end, when everyone had agreed on the goal plan document, Maria and her husband left the meeting happy. While this has been a long process with many interactions between the team members and Maria, later on during the rehabilitation, she did not remember everything, and she said that she didn't have a meeting to discuss the goals, which she actually had.

After this, Maria was ready to start/continue her rehabilitation interventions. The nurse printed the goal plan document and gave that to Maria altogether with the new weekly plan.

Among the sub-goals, Maria had "getting to know how much cognitive activities I can withstand" and "getting to know how much physical activity I can withstand". Each of them had their specific interventions, which were not dependent on each other, so working on them started at the same time. Another sub-goal related to these two was to *"have a plan for rehabilitation after discharge"*. The interventions related to this sub-goal started later in the rehabilitation process, after Maria had had an assessment of how much activity she could withstand.

Mapping the cognitive and physical capacity interventions

The OT scheduled a meeting with Maria to fill the MFS (Mental Fatigue Scale), which helped her to get to know how many activities Maria could withstand. The PT, who was in charge of the interventions related to physical activities, scheduled on the same day an individual time with Maria to test the balance and walking pace down at the training center of the hospital. The meetings were interesting for Maria, but she did not understand why she was doing all this. The OT and the PT had explained and reminded Maria why they were doing each of the activities, but as she was tired, she could not keep her attention focused and consequently remember everything afterward.

During the stay, she was, in most cases, being called in meetings by the healthcare practitioners. She was learning new techniques to cope with her situation. When she wanted to change an appointment, she had to go over to the healthcare practitioners to ask. That was not reflected in her paper calendar, so she had to remember to cross that over or write the new appointment somewhere else in her weekly plan. Moreover, the goal plan soon became another document in the file that Maria took initially, and she was not looking at it anymore. This because there was not much to do with it and because it was a very messy document that seemed overwhelming for Maria.

In the next weeks, Maria had group therapies such as mindfulness, VR group, tema kafe, etc. Other individual time therapies with specific healthcare practitioners such as a conversation about memory and memory strategies, where she had individual sessions with the psychologist, OT, and the nurse. Maria learned a lot of things regarding her condition. She learned how much activity she could handle and when she should take a break in her day. Moreover, she learned new ways on how to tell about her condition to others so they could also understand her challenges. She learned more about herself and became more aware of how the injury had changed her life and how she can get used to this new self and make the maximum out of it. The husband also learned new things about Maria's condition and how he could cope in a specific situation, and what activities they could do together without tiring her.

While Maria found the activities relevant, she lacked an understanding of how each of the everyday activities helped her. The healthcare practitioners explained how each session was contributing to her rehabilitation, but she said that she wanted to have it easier to see herself how each activity related to an intervention related to a sub-goal of one long-term main goal. Moreover, both the descriptions in the goal plan document and the weekly plan were so general that it was impossible to understand what the meeting was about until they had the meeting or remembered what was discussed with the healthcare practitioner in the previous session.

Moreover, during the weeks, her knowledge about her condition increased through the healthcare practitioners' very close care. She wanted to reformulate her goals in the fourth week, but it was too complicated to make changes to the document in the current condition, and there was no review session in the rehabilitation process that would allow such adjustments. So, nothing changed.

Preparing for discharge

Finally, Maria's time at the hospital was ending. She and her husband participated in the discharge meeting, where Maria was presented with the discharge report. The discharge report described her condition based on the initial assessment and some recommendations on how Maria should continue home. However, these recommendations were not specifically related to the goals. The whole report did not keep track of everything done, and with Maria's problem with memory would be difficult to remember everything done and tell that to local rehabilitation therapists.

2.3 Conclusion

In my first meeting at Sunnaas, I was introduced to the following questions as a research and practical interest by the hospital.

- How can we involve the patient more in the process of defining the rehabilitation goals?
- How can we make the rehabilitation goal-tool less static and more dynamic during the rehabilitation process?
- How can technology support the process of working with rehabilitation goals during the whole rehabilitation-process?

The questions above describe Sunnaas will for patient empowerment but questioned more in relation to processes and possible Information and Communication Technologies (ICTs) that can facilitate the services and the patient empowerment in rehabilitation.

These questions and the description of the rehabilitation process above show that while the patient has an important role in rehabilitation at Sunnaas, there is still a way to go when it comes to having a patient that owns her/his own rehabilitation and has control of the management of the rehabilitation process.

The goal plan document and the weekly plan are an example of cooperative artifacts between patients and healthcare practitioners, but in the current state, paper's affordance is limited and does not contribute to patients' empowerment.

In Maria's case, her involvement in defining her rehabilitation goals and interventions is present. However, Maria seems to not understand the whole process and why she is involved in activities. While she is part of shaping the discussion around her treatment decision-making, she is neither initiating the definition of her goals nor finalizing them herself. Moreover, in the interaction with healthcare practitioners, there is a cooperative relationship established in which the healthcare practitioners try hard to provide Maria with the support needed, but some things are "lost in the translation". For example, after the meeting with the OT, Maria does not remember some of the things they discussed. She also had difficulty in understanding how the activities at the department are related to her goals. Even though the healthcare practitioners repeat it for Maria, she sometimes forgets, or she can not focus, and the information just flies. This created challenges in Maria's understanding of her rehabilitation process and also in the ability to gain control.

Hence, there are practices in rehabilitation that present a good example of empowerment opportunity for the patient. However, there are still challenges that rehabilitation settings face. Thus, understanding them and building on what needs to be done next to contribute to empower patients is relevant.

The concern on the involvement in co-design of people with MACI came from my interest in Participatory Design (PD) practices and the lack of research in PD with this specific user group. Maria's vignette also highlights the challenges that MACI people have, which should be considered during co-design. Maria has memory, attention, and fatigue challenges. Moreover, her executive functioning also has been influenced by the illness. These cognition impairments are relevant during co-design to make participants be able to genuinely participate in the process and influence the decision-making and the design outcome.

Moreover, Maria's case shows how Maria is very dependent on healthcare practitioners. Thus, involving her in the co-design process with her healthcare practitioners might influence how much she will be engaged in the process. The differences in power/knowledge and the differences imposed by the healthcare system structure with a paternalistic approach toward patients, and the cognition challenges that MACI patients have, calls for considering these differences in power in co-design sessions. This is especially relevant in the design of cooperative artifacts in which both stakeholders are interested and should influence equally the outcome.

CHAPTER 3

THEORETICAL BACKGROUND

"A healthy vision of the future is
not possible without an accurate
knowledge of the past."

Daisadu Ikeda

In this chapter, I provide a theoretical background to my research. A large body of research has been devoted to the main concept of this thesis, “Empowerment”. However, defining empowerment is complicated because it takes different forms in different contexts. In this chapter, I initially present how empowerment has been discussed in the literature. Then, I focus on reviewing empowerment in two contexts: co-design and rehabilitation, and investigate more in-depth previous research on empowering practices and artifacts in each context. Building on the theoretical framework and the gaps found in the literature, I finally define my understanding of empowerment and position this thesis in the empowerment theory.

3.1 Empowerment: Definition and Theory

Analyzing the concept of "empowerment," Gibson (1991a, p. 354) in 1991 starts her paper by stating:

> “Today, empowerment is a popular word that is being applied to a variety of phenomena: the women’s movement, the Black Power movement, gay rights, empowerment of people with AIDS, student empowerment, empowerment of adolescents, empowerment of teachers, and empowerment of nurses - to note a few.”

Even though we are three decades later, that statement is still valid. The call and challenges for the empowerment of different social groups continue. Maybe the situation is not the same as in the ’90s, but new challenges have emerged, and the society is in constant change toward an attempt for balancing powers and empowering those social groups that are still in a power weak position. Hence, making the empowerment discourse highly relevant.

The word empowerment comes from the Old French prefix ‘en-’ meaning ‘in, into’ and the root ‘power’ that comes from the early 1300s, meaning ‘ability, strength, might, able to’. Though the word “empower” has been used in the past in literary works, its modern usage dates from around 1986[1].

So, literally, empowerment means “to power”, creating an inevitable link with the “power” concept. This made me investigate more on what power is and how it has been discussed in the literature.

Understanding power

In power literature, there are two contrasting views on the concept: first, power as domination, largely characterized as ‘power over’, and second, power as empowerment, frequently theorized as ‘power to’ (Haugaard, 2012).

Power as domination is associated with what is called a zero-sum power, where power is seen as energy, that only changes form. If one group gains power, it means that the power is taken from another group. This idea of power as domination, has been defined as ‘power over’ by Pitkin (1993). ’Power over’ is the power of getting someone to do something that they would not do otherwise. It also means for the person having power over someone, being in the position to do something to the others.

Power as empowerment is associated with what is called the positive-sum power in which one party does not gain power at the expense of the other. Rather, the power of both is expanded. Power as empowerment has been defined as ‘Power to’ by (Pitkin, 1993) and denotes agency, capacity, potential, ability to shape action, which is partly influenced by access to organizational resources or power/knowledge in a Foucauldian sense.

While “power to” is usually considered as the good kind of power, power over is usually discussed with a negative connotation.

Haugaard (2012) in his analysis of power dimensions, has discussed that ‘power over’ is not always about domination and something to fight against. He argues that actors can prevail over each other in ways that may be beneficial to those who are being prevailed. This is called benign paternalism, entailing what is considered ’concerted power’. Haugaard (2012) discusses that such power over is relevant for the functioning of the societies. The existence of structural power is not always negative, and some structures are needed in society to provide predictability of the events in different situations.

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[1] https://www.macmillandictionaryblog.com/empower

The way how power has been conceptualized in the literature has also influenced the empowerment discourse, where empowerment has been discussed as the way to power or as the destination of power.

Understanding Empowerment

Many researchers have investigated empowerment and elaborated individual definitions of empowerment. Rappaport (1995, p. 2) in her study of empowerment states that it is difficult to define a concept like empowerment because it “takes on a different form in different people and contexts”. Funnell and Anderson (2003) state that “empowerment is a vision or a philosophy”. So, it is very challenging to define, discuss and study such a vision in more practical and concrete terms. However, Rappaport (1995, p. 798) states:

> "Indeed, I think that ultimately it is quite useful to find terms that engender public debate about social issues, and while I am as willing as other progressives to disapprove of many of the ideological and action aims of certain groups that claim an interest in empowerment, I find the debate more useful than not...As a practical matter, all that is required is that one declare, in any particular context, exactly what empowerment means, as indeed these authors do."

Rappaport is saying that despite the complexity of the concept, which can create confusion in many cases, it is more important to have such discussions as means of social changes and development, than not having them at all.

She refers to the definition of empowerment given by the Cornell University Empowerment Group, where is stated that empowerment is:

> “an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources” (Cornell University Empowerment Group, 1989, p. 2 as cited in Rappaport (1995, p. 802)).

Hence, empowerment is defined as a process in a community where people share with each other resources and where some people that lack an equal share of the resources gain access and control over the resources. The definition provides an interesting perspective of who is empowered (a group of people) and where the empowerment discourse and process happens (in the community and the community’s relationships in the sharing of the common resources).

This definition has similarities with Hardy and Leiba-O’Sullivan (1998) analysis on the elements of empowerment defined as: 1) gaining access to the decision-making arena, 2) gaining needed resources and the ability to utilize those, 3) gaining a will to resist the ones in power (in line with a conflictual approach of power) and 4) a more positivist view in Foucauldian terms, where the power is embedded in the system, and the exercise of power in local setting can generate some form of benefit. Hardy and Leiba-O'Sullivan (1998) plead that to achieve empowerment, the four dimensions of power should be analyzed and adequate measures applied.

Thus, empowerment in the above definition is associated with some form of control and participation in managing resources. While in the definition by Cornell University group is not made clear how the control and participation can be achieved, this is more foregrounded in Hardy and Leiba-O'Sullivan (1998), where either resistance to power or collaboration and cooperation with the existing current powers can enable the way to empowerment. Foucault (1982) discussed a connection of power and knowledge and the ability to develop the power to increase the knowledge base. Freire discussion of power and empowerment in the "Pedagogy of the oppressed" (Freire, 2018) also considers education and knowledge as an important part of empowerment. Thus, adding knowledge acquisition and knowledge management as an important enabler of empowerment.

However, knowledge, control, or power are sitting in between groups of people. Empowerment is a transactional concept that involves a relationship with others and some form of collaborative effort (Gibson, 1991b; Kieffer, 1984; Zimmerman, 1990). It is not confined only to the person itself, but to how the person creates relations in the environment around. Katz (1984) sees empowerment with a synergic paradigm, where people are interrelated, there is a sharing of resources, and collaboration is encouraged. The empowerment process entails mutually beneficial interactions that strengthen rather than weaken the mediating structure between the individual and the society (Rappapon, 1984). This should capture all the social, political, and economical aspects. Hess (1984) has proposed a system approach to study empowerment as it is a multidimensional concept.

Empowerment is a dynamic concept where power is both taken and given (Hess, 1984). In other words, power is shared (Hegar & Hunzeker 1988). There is a need to consider not only how the 'powerless' attempt to take power but also how the 'powerful' release power argues Rappapon (1984). However, this does not mean empowerment is necessarily conflictual. Empowerment is a developmental concept where individual, family, and community growth and potential are enhanced. To bring radical changes sometimes needs fights against the existing structures and making root changes and for that Gibson (1991b, p. 355) states that "empowerment is more revolutionary than reformist".

Kinnula et al. (2017b) in the analysis of empowerment of children in the design of new technology, discuss empowerment as related to the concepts of competencies, combat, and cooperation. Competence is a concept that can be set in analogy with knowledge gaining, control, and participation in decision-making in resources management. Instead, combat and cooperation are two concepts that reflect how the competencies are applied to move toward empowerment. Combat and cooperation are not two mutually exclusive ways. Combat can be related to the need to change the current power structure, and cooperation can be the road toward the new redistribution of power.

There are two different views on empowerment that prevail even today. The first is functional empowerment associated with the increase of a person's capability to be more efficient when performing a specific task and, consequently, contributes to the organizational goals that are supposed to be shared unproblematically (Clement, 1996). In this view of empowerment, the organization's management empowers employees to be more efficient, but they do not consider their voice when deciding to do so. This has also been defined as the managerial view on empowerment (Hardy and Leiba-O'Sullivan, 1998). It has been critiqued by other scholars belonging to the critical tradition, who argue that empowerment can never happen through those having power giving some of it to the power-weak.

Second, democratic empowerment is that view of empowerment in which people are encouraged themselves to gain more control of their lives, and "to act with a greater grasp and sense of their own powers"(ibid). This touches on people's rights and abilities to decide on issues that concern them. So empowerment is not given to people but comes as a consequence of collective action. This empowerment seeks emancipation from subordination in oppressive institutions and is directed toward creating conditions for independent individuals in a society of free cooperation and communication.

Democratic empowerment is the desired one and what is closer to the usage of the empowerment concept today, where a group of people gain access and control over something with their own initiative. However, functional empowerment is quite common in society, especially related to new tools and artifacts created to facilitate people's daily lives and increase their participation in society. The two views of empowerment are related to each other.

Empowerment is associated with changes and transformation in society and the social order. A critical factor of social transformations has been computerization. Kling three decades ago (Kling, 1991, p. 344) states that "computer technologies can play key roles in restructuring major social relationships - interpersonal, intergroup and institutional". Time has shown that technology has influenced and enabled a wide range of social transformations that have gone beyond people's imaginations and changed everyday life at home or workplaces. Technology is seen both as an element that can enable functional and democratic empowerment. Having the right tools and technologies to enable empowerment is important. Thus, taking empowering technologies in consideration when discussing and studying empowerment can contribute in a positive way.

As you notice in this subsection, empowerment is a concept that has been defined in different ways and in different perspectives. In this thesis, I use as a main definition of empowerment the one presented by Rappaport (1995) as cited above. I focused more on understanding empowerment in terms of knowledge, control, participation in shared resources, and cooperation in the management of those resources. The empowerment theory presented below will be used as the theoretical framework for this thesis.

Empowerment Theory

Relevant to my understanding of empowerment has been the work of Mark Zimmerman and colleagues (Zimmerman and Warschausky, 1998; Zimmerman, 2000; Perkins and Zimmerman, 1995). Zimmerman (1990) has focused initially on understating empowerment at the individual level and has called it psychological empowerment. Psychological empowerment (PE) integrates perceptions of *personal control*, *participation* with others to achieve goals and a *critical awareness* of the factors that hinder or enhance one's efforts to exert control in one's life. Zimmerman (ibid) highlights the relevance of perceived control and participation as a motivation to request more control and influence the decision-making process. Thus, he sees PE as starting with the individual self but put in context with the relationships and the organization or the community in which the person lives. This is similar to Freire's perspective who places the individual within the context of a group or community as they develop the personal skills and social resources to create change and fight oppression.

Zimmerman and Warschausky (1998) have described a multi-level construct of empowerment compounded by psychological empowerment (PE), organizational empowerment (OE), and community empowerment (CE).

At an organizational level of analysis, empowerment includes processes and structures that enhance member participation and improve organizational effectiveness for goal achievement. They (ibid) differentiate between empowering and empowered organizations.

Empowering organizations are those which provide opportunities for individual growth and access to decision-making processes. Empowering organizations are cooperatively controlled by their members and work toward goals defined by those members, within the parameters of external opportunities and constraints (Schulz et al., 1995).

Empowered organizations are those with control and influence over their environments and the ability to affect the distribution of social and economic resources.

Instead, at the community level of analysis, empowerment may refer to collective action to improve the community's quality of life and the connections among community organizations and agencies.

While Zimmerman and Warschausky (1998) describe these three levels of empowerment, in Melander Wikman and Fältholm (2006) it is highlighted yet another level: group/team level of empowerment. Like the organizational level of empowerment, team empowerment is also based on the structures and practices that enable a team to work together by encouraging team members to gain power (Ghaye, 2008).

Schulz et al. (1995) argue how these levels of empowerment are interrelated with each other. Empowerment on the team and organizational level need individuals that are pursuing psychological empowerment. Instead, psychological empowerment is achieved with the individual gaining power in the group, organization, and community and act to opportunities for social support and development of interpersonal and social or political skills (Zimmerman, 1990). Empowerment requires a combination of action and reflection on every level. Perceived influence at the organizational and community levels both shapes and is shaped by perceptions of individual control.

Zimmerman and Warschausky (1998) also describe three dimensions to be considered in empowerment theory — values, processes, and outcomes — as an effort to provide a consistent framework for research.

- **Empowerment values** relate to values that resemble empowerment, such as aiming wellness or competencies building.
- **Empowering processes** are described in Zimmerman and Warschausky (1998, p. 5) as "The mechanisms through which people, organizations, and communities gain mastery and control over issues that concern them, develop a critical awareness of their environment, and participate in decisions that affect their lives." Critical awareness is defined as "one's knowledge of how to acquire those resources and the skill to manage the resources once they are obtained". While perceived control and critical awareness are elements to consider in the empowering process related to the individual level of empowerment, at the organizational level, relevant processes are deemed structures that encourage involvement in decision-making, sharing responsibilities and skill development.
- **Empowerment outcomes** are the results of empowering processes and are used as measurement mechanisms. Zimmerman and Warschausky (1998, p. 6) state that "although empowerment outcomes generally refer to control, awareness, and participation, these may also be operationalized differently across levels of analysis".

The three dimensions highlighted make empowerment easier to operationalize and research in practice. The three dimensions can be explored in each of the levels of empowerment described above (Zimmerman and Warschausky, 1998). Zimmerman and Warschausky (1998) present some empowerment processes and outcomes for the individual, organizational, and community level.

However, empowerment is relational: the individual in relation to the society - being this a group/team, an organization or the whole community (Gibson, 1991a). To achieve empowerment outcomes for a specific individual, empowering processes that involve the individual and the relation s/he has in the context around her/him should be taken into consideration.

In this thesis, I build my understanding of empowerment in Zimmerman and Warschausky (1998) multi-dimensional empowerment theory having as the locus of empowerment the group and aiming that through empowering processes in the group/team cooperation contributing to empowerment outcomes for the individual which in my two contexts would be: patients in rehabilitation and people with Mild Acquired Cognitive Impairments (MACI) in co-design.

As presented in the introduction, while Zimmerman and Warschausky (1998) use the term processes, I have found the term delimiting as processes are usually described as well-defined steps that achieve a predictable result. In this thesis, I have adopted the concept *"practices"*. The term practice is used to refer to what people really do, in contrast to what they are expected to do in more formal accounts of activities. Schmidt (2014, p. 10) in his analysis of practice as a concept defines it "as normatively regulated contingent activities", referring to more vigorous activities that are influenced by the situation. In Simonsen and Robertson (2012, p. 8), they state that "practice evolves over time as practitioners actively engage in reviewing and modifying their practice in response to all kinds of changes and developments, not just those resulting from the introduction of new technologies". Empowering practices have been previously used to describe empowerment of nurses or patients (Kettunen et al., 2001; Daiski, 2004). Ehn (1993, as cited in Brandt et al. (2012, p. 148)) provides another description of the practice concept which is relevant in the design field: "Through practice we produce the world, both the world of objects and our knowledge about this world. Practice is both action and reflection. But practice is also a social activity, it is produced in cooperation with others." Hence, practice as described in each of the definitions highlighted captures better than "processes" what happens in reality in implementation of empowerment.

The scope of the thesis are the empowering practices in rehabilitation and empowering practices in co-designing with the MACI people. In order to investigate practices, I should initially have an understanding of the empowerment outcomes that the empowering practices should contribute in both contexts. Patient empowerment and empowerment in co-design have been researched previously. I build my understanding in co-design on the field of Participatory Design (PD).

Hence, I review what has been described in the literature as empowerment outcomes in these two contexts. Then make use of these outcomes as the basis for investigating empirically the empowering practices building on the narratives of peoples whose empowerment is being discussed.

3.1.1 Patient Empowerment: Participate, Control, Understand and Cooperate

Patient empowerment discourse is recognized as an "essential element of high-quality healthcare systems with regard to tackling the expanding burden of chronic diseases" (EHP, 2015).

Before presenting the definition of patient empowerment I want to review what is the meaning of the word "patient" as empowerment has already been reviewed above. The word patient originally meant "one who suffers". This English noun comes from the Latin word "patiens" which is the present participle of the deponent verb, "patior", meaning "I am suffering", and akin to the Greek verb – paskhein meaning "to suffer" and its cognate noun pathos which is used to refer to compassion[2]. So, a patient is someone in a weak position who is suffering due to her/his health and it awaken a feeling of compassion in others.

The term "patient" has been criticized in the literature due to the weak position in which it portrays the person in need. Alternative versions have been used to refer to people in need, such as care recipient (Bratteteig and Wagner, 2013) or just using "person" if the patient is not at the hospital (Eide et al., 2017). This change in terminology is an attempt to change the patient's position from a passive actor into an active one who is involved in her/his care and contributes with her/his unique experiences as much as the healthcare practitioners.

Patient empowerment is usually closely used with patient involvement, patient engagement, collaborative care, etc. These definitions have their drawbacks as they either push too much pressure on the patient or do not consider the patients' genuine participation in their care. Another used concept is patient-centeredness. This can be the goal of an encounter between a patient and caregiver. Having the patient in the center of care services is of great value in empowering the patient. However, patient empowerment is broader than patient-centeredness and may place greater demands on caregivers and the organization of healthcare (Holmström and Röing, 2010).

There are different definitions of patient empowerment (Bravo et al., 2015; Barr et al., 2015) and also different models (Umar and Mundy, 2015). Roberts (1999) in a critique commentary states that the concept can still be classified as fuzzy and black-boxed. In most cases, patient empowerment is seen as an umbrella of a set of principles to consider in organizing healthcare, which would define an empowered patient (Fumagalli et al., 2015; Anderson and Funnell, 2010; Holmström and Röing, 2010). Hence, in analogy with Zimmerman and Warschausky (1998) empowerment theory, patient empowerment is mostly described in empowerment outcomes even though they are not directly defined as such.

In this thesis, I adopt the definition of an empowered patient given by the EU-funded project called EMPATHIE ("Empowering Patients in the Management of Chronic Diseases") as cited in EPF (2015, p. 5).

> "An empowered patient has control over the management of their condition in daily life. They take action to improve their quality of life and have the necessary knowledge, skills, attitudes, and self-awareness to adjust their behavior and work in partnership with others where necessary to achieve optimal well-being.....Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to participate in decisions related to their condition to the extent that they wish to do so; to become "co-managers" of their condition in partnership with health professionals; and to

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[2] https://www.etymonline.com/word/patient

> develop self-confidence, self-esteem and coping skills to manage the physical, emotional and social impacts of illness in everyday life.” (citet later in the scientific article by Bedlington (2016))

Deriving from this definition, the European Patient Forum (EPF) expands on four relevant areas to position the discussion and analysis of an empowered patient:

- **Meaningful involvement** – relates to the right and duty of patients “to participate individually and collectively in the planning and implementation of their healthcare” (WHO, 2017). The patient holds the expertise in his/her condition, so it should have a more determinant role in her/his treatment.
- **Health literacy** – means having sound knowledge of your condition, which will lead to better health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the marketplace, and the political arena” (Kickbusch et al., 2005).
- **Self-management** – stands for the support that the patient should get to live with the condition s/he has in the best way. Self-management support aims to build among patients the confidence, self-efficacy, and skills to control their daily life and attain the greatest possible quality of life. This also helps to make the best use of all available resources by, for example, improving adherence, reducing hospitalization and emergency visits, and improving health outcomes.
- **Shared decision-making** – stands for patient-healthcare practitioners relationship as a partnership of equals. The patient’s involvement should be accepted by the medical counterparts, which welcomes the patient’s participation in her/his treatment.

Cited from Çarçani et al. (2019, p. 2).

These four discussion areas are indeed empowerment outcomes. A patient to be considered empowered should be meaningfully involved in her/his care, participate in decision-making regarding the care treatment, achieve a certain level of health literacy, and manage and care for the self. The reason I have presented these outcomes extensively is because in Paper I, I use this model of outcomes of empowerment as the main model of patient empowerment. In this thesis, I extend the review of the literature as presented in the next paragraphs and reflect and conclude with some other outcomes that slightly change from the ones above.

Chiauzzi et al. (2016) studying patient empowerment have highlighted two main factors influencing empowerment. These are positive patient-provider interaction, and knowledge and personal control. Chiauzzi et al. (2016) explain that the positive patient-provider interaction factor includes items related to patient satisfaction, comprehension, and active involvement in treatment. On the other side, they see empowerment as a sense of self-efficacy in health information seeking and a positive co-creating relationship between patients and providers (Aujoulat et al., 2007). Small et al. (2013) have defined some similar outcomes of patient empowerment that they refer to as factors. The outcomes are having 'knowledge and confidence in decision-making' and 'positive attitude and sense of control'.

Palumbo (2017) argues that only enabling patients' knowledge and cognitive skills is not enough to establish an active role in the healthcare delivery system. Once enabled, the cognitive skills of patients need to be activated (ibid). To achieve this, a positive patient-provider relationship is crucial and will enhance patients' awareness of their role in co-planning, co-designing, and co-delivering health services, paving the way for greater self-efficacy perception and, consequently, stronger engagement (Chiauzzi et al., 2016; Palumbo, 2017).

Reflecting on the previously presented literature I have concluded and summarized the empowerment outcomes in relation to individual empowerment of patients as:

1. The patient participating throughout the whole treatment process where participation is seen in the discussion and decision-making regarding the treatment – I have decided to use the term participation instead of involvement because participation entails a more active form of being involved in which you are not just part but also influence the decision-making.

2. The patient gaining understanding and health literacy (getting knowledge and understanding regarding condition and treatment) – in all the reviewed literature, access to information, getting knowledge, and achieving health literacy are mentioned. However, a person can have knowledge about something, but if they don't understand it, they cannot make use of the knowledge. Hence, I see the understanding of the treatment as closest to health literacy.

3. The patient having control over her/his treatment by influencing the decision-making – Among the factors listed above, self-management, self-efficacy, influencing decision-making were mentioned. These are related to the patient's ability to control her/his care process.

   However, a relevant factor of patient empowerment presented above was shared decision-making and a positive patient-provider relationship. Hence, another outcome of patient empowerment which is an outcome for the individual patient and for the group/team that compounds the patient care network is:

4. Strong cooperation between patient-healthcare practitioners – The cooperation should enable patients to understand, control, and participate in their care.

While the empowerment outcomes focused on the patient have been discussed and studied, the necessity for cooperation is usually overlooked in the studies of patient empowerment where (in a way understandable) the stress is put only on the patient, and the healthcare practitioners are seen as fitting a patient-led agenda. Palumbo (2017) in his book titled "The bright and the dark side of patient empowerment" states that if the cooperation is not discussed and negotiated from the perspective of patients and healthcare practitioners, it would lead toward value de-construction in the healthcare sector, and healthcare practitioners will not embrace the changes.

Umar and Mundy (2015) study is also in line with the outcomes I presented above. However, their study brings in focus on the empowerment discourse the role of technology in enabling empowerment by contributing to awareness on the healthcare information, knowledge as having a certain level of health literacy, partnership as involvement in the definition and management throughout the treatment, and self-efficacy.

Umar and Mundy (2015) study is not the only one that mentions technology as an empowerment element. The role of technology in patient empowerment has also been highlighted by Palumbo (2017). Different kind of technologies such as technologies for Activities of Daily Living (ADL) has contributed to functional empowerment. Instead, other patient portals, Personal Health Record (PHR)(s) have contributed to democratic empowerment. Hence, referring to the empowerment theory I presented above, not only empowering practices but also empowering artifacts can contribute toward specific empowerment outcomes.

The empowerment outcomes listed above are focused on an empowered patient on the individual level. To make possible such empowerment as patients enter in cooperation with healthcare practitioners and one another, their groups or teams or the health organization should be taken in consideration as well. Thus, when I study empowering practices I focus on the group/team and organizational level of empowerment.

While empowerment outcomes in healthcare are widely discussed, there is a lack of operational models of empowerment that can be easily adapted in healthcare. That is where I contribute through this thesis. However, I don't aim to present a model that can be adopted in every healthcare domain. I study and describe empowerment practices in rehabilitation.

3.1.2 Empowerment in Participatory Design: Having a say, Influencing decision-making, Influencing the design outcome

In this subsection I present a short history of Participatory Design (PD) and its main principles. The reason I start with this is because the history of the PD field starts exactly with the struggles for empowerment of different groups around the world. Moreover, the principles of PD are built around empowerment and ways to approach the imbalances in power. I discuss below how the principles are in analogy with Zimmerman and Warschausky (1998) empowerment theory for researching empowerment.

PD flourished among the various social, political, and civil rights movements of the 1960s–70s when people in Western countries required more and stronger rights on the decision-making in situations of shared interest and values (Bjerknes and Bratteteig, 1995). PD is a principled design approach that is based on the idea that those who will be affected by the design of new information technologies or digital artifacts, should have a say during the design process of these technologies. The user should not only have a say but also influence the outcome (Bjerknes and Bratteteig, 1986). PD has at its core an ethical motivation to support how people can engage with others in shaping their world over time (Robertson and Wagner, 2012). In PD users are considered as “domain experts” of the realities in which they live, so they must undertake the role of the designers. Respecting people’s expertise and their right to represent their activities to others is relevant in PD (Robertson and Wagner, 2012).

Most importantly for this thesis is that PD is that design approach that is specifically concerned with the power discourse in the design process.

In this thesis, when referring to the practices of PD I use the term co-design defined as "collective creativity in design" by Sanders and Stappers (2008, p.6). Otherwise, I refer to PD as an approach when discussing co-design practices in conjunction to empowerment and power issues discourse.

PD started in the Scandinavian countries but was a consequence of a set of worldwide changes and movements before and during that moment, such as the involvement of citizens in Germany in shaping their local communities by participating in future workshops (Jungk and Müllert, 1987), or the feminist movement requiring changes in the woman role in the society, and the workers movement in protecting themselves from the de-skilling processes introduced by the management with the aim of increasing efficiency and profits in the workplace (Greenbaum and Kensing, 2012).

PD projects initiated almost simultaneously in Sweden, Norway, and Denmark. However, the work of Christian Nygaard, who in the early 70’s cooperated with the Norwegian Iron and Metal Workers Union (NJMF) to analyze problematics of new technologies in the working place and develop strategies to boost workers’ power in relation to management technology initiatives, is accounted to be the earliest PD project (Simonsen and Robertson, 2012). The idea of giving power to workers in the digitalization process came as a consequence of an increased contradiction between management strategies and workers, and the change in legislation, where workers were given the right to access more information regarding new technologies and decisions in their workplace (Greenbaum and Kensing, 2012). The NJMF project was the first project in which workers and trade unions were involved in the working place’s technology immersion process. The involvement of the workers’ voice represented in system design, became a representative of the Scandinavian design tradition and later, it spread to other countries and disciplines (Van der Velden and Mörtberg, 2014).

Despite the heated discussion for two decades, PD had its first conference in 1991 and has continued ever since by expanding the focus also outside the workplace and new user groups who similarly to the workers in the ′70s should have their voice heard in the design of technologies that influences their environment. Other projects such as UTOPIA in Sweden (Ehn, 1988) and DUE in Denmark were ongoing in the same period. Another project of strong relevance for this thesis due to the domain of research, healthcare, was Florence (Bjerknes and Bratteteig, 1986) which focused on building systems for nurses′ daily work.

In the Handbook of participatory design (Greenbaum and Kensing, 2012, p. 33-34) are listed a set of principles for PD. The first principle is the one of *″Equalizing power relations″* meaning giving voice to those who may be invisible or weaker in the organizational power structures. In order to make possible equalization of powers it is relevant to apply *″democratic practices″* that promote user genuine participation in the design process. Democratic practices require educated and engaged people who act on their interests and the common good. Moreover, democratic practices should be studied in *“situated based actions”*. This means to work directly with people in their contexts where the actions and the relations unfold. In situated democratic practices, *“mutual learning”* among stakeholders should be promoted, as a crucial principle of PD. To support the previous principles researchers and designers in PD should consider carefully the *″tools and techniques″* to be used in the co-design process. The principles highlight that enabling the equalization of power and thus empowering marginalized user groups can be done through tools and techniques. Bratteteig et al. (2012, p. 118) state that "techniques explain how to go about carrying specific activities, while the tools are concrete instruments supporting the techniques". Tools and techniques should enable *“alternative visions about technology”*.

Empowerment in PD is seen on the context of equalizing power relations. The equalisation of power relations can be done through cooperation or combat (Haugaard, 2012). However,in PD mutual learning should emerge, and each part should learn from each other and exchange experiences and values. The principle of mutual learning shows that PD embraces a more cooperative approach for the equalization of power in PD.

Reflecting on Zimmerman and Warschausky (1998) empowerment theory in relation to the PD principles, I argue that PD techniques and methods are in analogy with the empowering practices in the Zimmerman and Warschausky (1998) theory. Tools are artifacts that facilitate techniques and are an integral part of them. Tools in PD, as per definition, facilitate and support the empowering practices in co-design. Thus, they make up empowering artifacts in co-design.

As I stated above, mutual learning is another core part of PD. The aim is to create mutual respect between user groups involved in design for each other′s knowledge and enable learning about each other so they can understand the different ways of reasoning. Mutual learning and providing guidance on how to achieve that is a commitment in PD. So, mutual learning can be considered an empowerment value in the empowerment theory on which empowering practice would contribute to achieving this value. A democratic process also constitutes a value in PD.

I stated that I am interested in finding empowerment outcomes in co-design. Hence my question is, what characteristics should have an empowered person in co-design. As stated above, a user "having a say" in the design process is one of the empowerment outcomes. Bratteteig et al. (2012, p. 129) state that "having a say is more than just having a voice, it means affecting the outcome of an activity with what you say". Thus, having a say is the ultimate empowerment outcome in PD, enabled by democratic practices, mutual learning, and tools and techniques.

To understand more on what "having a say" entails, I refer to the extensive work of Bratteteig and Wagner (Bratteteig and Wagner, 2014, 2016a) in studying participation in PD, power, and decision-making. They have defined the user's influence in the decision-making in the design space as an aspect of power (Bratteteig and Wagner, 2014). The influence in decision-making will also be noticeable in the participatory design outcome (Bratteteig and Wagner, 2016b). Affecting the outcome means influencing or contributing to the decisions made and, in this way, influencing the design outcome. The design outcome may change based on the scope. The focus can be on the design outcome of a session or on the whole project's design outcome.

So, influencing the deciding-making in the co-design process and influencing the design outcome are empowerment outcomes in PD. I want to argue that "having a say" is also an empowerment outcome in PD on its own and not only an umbrella term for influencing decision-making and design outcomes. I consider "having a say" as the ability to contribute in the co-design with design ideas that will be considered in the design space. Hence, having a say as not only having the voice that is given to you through participation but also including the possibility to envision ideas that can be equally evaluated in the design space and have the potential to influence the decision-making and the design outcome.

For example, if the designer comes up with some design ideas and the users evaluate them and decide what is suitable and these decisions are then represented in the final design outcome, represent a PD process. However, enabling the users to have a say from the start and ideate design ideas would comply more with PD principles. It is the mutual learning process that contributes to users having a say in articulating design ideas.

Based on the arguments presented above, I have concluded and summarized three empowerment outcomes in PD. These are:

- Have a say - enabling participants to articulate their design ideas and needs so they can make a significant contribution in the design space.
- Influence decision-making - enabling participants to be able to influence the decision-making in a co-design project.

- Influence the design results - seeing the voice and the decisions of the participants represented in the final outcome of the co-design project.

Each of the dimensions of empowerment in Zimmerman and Warschausky (1998) should be considered for each of the levels of empowerment. However, as Zimmerman and Warschausky (1998) state, the levels are interrelated with one another.

The empowerment outcomes listed above refer to psychological (individual) empowerment and also to the group/team of people in the same position, during co-design. In my study these are MACI people and the outcomes of empowerment aim every MACI participant in the PD workshops and also their empowerment as a group/team.

Instead for empowering practices, I have studied them at the level of group/team and organizational, by focusing on how to arrange PD sessions to make the MACI people or the MACI person empowered in the co-design process.

3.2 Previous Research

In the previous section, I discussed empowerment outcomes in the case of patient empowerment and empowerment in co-design. In this thesis, I am concerned wit empowering practices and empowering artifacts for patient empowerment in rehabilitation and for empowerment of MACI people in co-design. Hence, in this section I review previous research on empowering practices and artifacts in each of the contexts.

I initially present some discussion on empowering practices in rehabilitation and also some previous empowering artifacts for patient empowerment in rehabilitation. As in rehabilitation one of the main elements of the empowerment outcomes is to strengthen cooperation between patients and healthcare practitioners I have also reviewed Computer Supported Cooperative Work (CSCW) in rehabilitation in relation to the topic of patient empowerment.

I then review the empowering practices and empowering artifacts used to co-design with people with cognitive impairments.

3.2.1 Empowering practices in rehabilitation

Empowering patients have been found beneficial in improving rehabilitation (Wang et al., 2007; Löfgren et al., 2015). The rehabilitation *per se* has an empowerment value focused on the well-being of people in need of rehabilitation (ibid).

In rehabilitation literature, the empowerment discourse is always mentioned between the lines, and the empowerment outcomes are the same as generally with patient empowerment: participation in decision-making, understanding, control, and most importantly, cooperation with healthcare practitioners.

There are few empirical studies on empowering practices in rehabilitation. Of relevance is the work of Melander Wikman and Fältholm (2006) who have studied patient empowerment and patient involvement in rehabilitation empirically. They found that in an acute rehabilitation setting, a more traditional way of care is adopted, in which the patient is a more passive actor. Instead, a new model of care is adopted in primary care settings. Rehabilitation services are not only patient-centered but also imply significant patient involvement in the process. However, analyzing in-depth the involvement of patients in their rehabilitation process, Melander Wikman and Fältholm (2006) found that there is a difference between the perception of involvement and influence in decision-making between patients and their healthcare practitioners. They investigated aspects that undermine patient empowerment in the rehabilitation process and found that compliance and sub-ordinance of patients, who mostly agreed with the healthcare practitioners, would make them less empowered in practice. Instead, being confirmed, searching for information, daring to demand, and getting a sense of coherence were among the elements that made the patients feel empowered in rehabilitation.

Hunt (2014) presents another study that investigates the rehabilitation practices in regard to patient empowerment. However, she focuses on the practices of Occupational Therapist (OT) and how they contribute to patient empowerment. She found that by using facilitative communications such as reflective listening, OTs may be better equipped to bridge the gap between client-centered expectations and clinical practice in goal setting. Rehabilitation is not only based on OTs interacting with patients. The patient usually is in cooperation with many healthcare practitioners. This makes cooperating more complex. Hence, Hunt (2014) findings are relevant also for other healthcare practitioners and their way of communicating with patients.

As presented in Chapter 2, goal setting theory is central in the rehabilitation model. It requires strong cooperation between a patient and her/his multidisciplinary team. However, Plant and Tyson (2018) found that the goal-setting process is not always as smooth as in the theoretical description of it. Usually, the setting of goals is healthcare practitioner-led with strong cooperation between the multidisciplinary team members. Moreover, Plant and Tyson (2018) found that monitoring progress and revising goals is not common, and sometimes the goals and treatment, action plans, and progress were somehow inconsistent.

Furthermore, Rose et al. (2019) have studied shared decision-making (SDM) in goal setting. They found a set of drawbacks on how patients and healthcare practitioners perceive shared decision-making involvement. They found that patients set a high price to the motivation in being involved in the process. However, they said patients felt insecure about participating in SDM and speaking up. Moreover, their findings show that patients' confidence increased with a close family's involvement in the process. Patients perceived a paternalistic approach in some cases. In others, they felt they could not understand the staff's terminology, struggle to follow during the meeting, and, consequently, forget what they discussed later. The authors say that the patients highlighted that it is important for them to feel heard. Some patients felt dis-empowered because their opinions were not considered by healthcare practitioners, leaving them feeling their views were not valuable. Consequently, patients would not want to speak up, especially if healthcare practitioners were also not listening. Another problem presented in the paper is that patients did not feel like having a choice when setting their goals. Despite the problems in cooperation, patients' experiences and willingness to be involved in the decision-making regarding their goals differed. They (ibid) also found that to be more involved in decision-making, patients wanted to have more knowledge regarding their rehabilitation options, have a clearer explanation of the goal-setting process, and have some form of decision support. In the paper, they state: "Sophie used a form of agenda-setting ... that supported her decisions on goals.. "I wrote a list beforehand of what I wanted to talk about in the meeting and my ideas on my goals" (Rose et al., 2019, p. 570).

The studies presented briefly above are examples of challenges in rehabilitation that undermine empowerment. However, they also represent cases where the patient voice has been heard in regard to rehabilitation and rehabilitation practices. Melander Wikman and Fältholm (2006) study is the only one closer to the findings presented in this thesis. Nevertheless, their study is more descriptive in comparison to the constructive approach in this thesis. Here the focus is on investigating what we can do and what practices we should consider to empower patients in rehabilitation. Rose et al. (2019) study also is relevant when it comes to challenges in practices of decision-making. They also highlight some positive elements that can motivate patients to be stronger actors in the decision-making. These elements are of interest to this thesis.

More empowerment studies in rehabilitation come from the rehabilitation domain, in which empowerment of patients is considered as one of the rehabilitation outcomes. These studies highlight more clinical interventions from an educational perspective of the patients in self-management that will improve their clinical condition and better manage their lives. However, there is a lack of studies regarding the organization of empowering practices in rehabilitation, especially when it comes to the investigation of such practices through the voices of patients and their rehabilitation healthcare practitioners. Hence, this thesis contributes in this direction by focusing on investigating empowering practices in rehabilitation.

3.2.2 Technologies supporting patient empowerment processes in healthcare and rehabilitation

Information and Communication Technologies (ICTs) are considered as an enabler of patient empowerment which can support the patients' capability to get access to the care services, information, and decision-making in their care and do this in partnership with healthcare practitioners who are positive toward allowing the patient to be more part of their care and share some of the care tasks with them (Danis et al., 31 Dec. 2015). So, ICTs can contribute to empowerment outcomes by supporting and enhancing empowering practices.

However, I am interested in patient empowerment in rehabilitation. Different types of technology have been considered as contributing to different aspects of patient empowerment in rehabilitation. Some technology examples are wearable, digestible, implantable, social media, games, cognitive computing, apps, chat-bot, VR, etc. (Lee et al., 2015). These technologies, in most cases, contribute to the functional empowerment of the patient by providing tools that can support her/his function better in everyday life. For example, Assistive Technologies (AT) have supported people to be more independent, increase their personal knowledge and capabilities (Frank Lopresti et al., 2004; Rispoli et al., 2014). Some examples of research are presented in the following papers: (Cameirão et al., 2016; Webster and Celik, 2014; González-Calleros et al., 2014; Steinisch et al., 2013; Lehrer et al., 2011; Prashun et al., 2010). Some commercial examples are NYOYN[3], REHACOM[4], Constant Therapy[5], etc. So, technology has contributed to increasing people's individual abilities and supporting rehabilitation therapy sessions.

However, other technologies have contributed to more democratic empowerment and have had as central the empowerment of patients in terms of control of their treatment, knowledge, and understanding of the treatment and also participation and shared decision-making in cooperation with healthcare practitioners. As also stated above, the latest type of technologies are those on which this thesis is focused.

An example of such technologies are the patient portals (Deering and Baur, 31 Dec. 2015). The design of such portals poses security questions, but their design contributes towards giving patients access to health information and communication with healthcare practitioners. Additionally, telehealth is considered to have a high capacity to contribute to patient empowerment when it comes to strengthening the relationship between patients and healthcare practitioners when they are not in the same place.

An important role as part of ICTs for patient empowerment, play mobile solutions. van der Heijden et al. (2015) describe the case of a smart care - assistant m-health solution which includes functionalities such as inpatient data collection, intelligent models that facilitate decision-making, and concisely visualize the health information. These can all enhance health literacy. Mobile apps have been adopted to give patients access to health data information, or healthcare practitioners to give the possibility to monitor the patients and promote different health habits that can bring improvement in functioning in everyday life.

Calvillo et al. (2015) also have conducted a literature review on how technology is empowering patients. They found that Web services are among the most used technologies for empowering patients and supporting services in the health domain. Moreover, other technologies such as blogs, forums, social media, and mobile apps are also being used as infrastructure for

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[3] http://www.nyoyn.com/en/occupational-therapy/

[4] https://hasomed.de/en/products/rehacom/

[5] https://constanttherapyhealth.com/constant-therapy/

enabling search and share of information and support the communication among patients and professionals and strengthen the continuity of care beyond physical appointments.

While Electronic Medical Records (EMRs) have revolutionized the management of health records and facilitated clinicians' work, another more recent development that is considered a contribution to patient empowerment are Personal Health Records (PHRs) (Calvillo et al., 2015).

PHRs have been defined generally as "internet-based, lifelong health records controlled by the individual and are meant to promote the individual's engagement in his or her health and healthcare" (Davidson et al., 2015, P. 192). Davidson et al. (2015) in a PHR literature review found that there are different types of PHRs. One type of PHRs are those tethered to an EMR. In that configuration, part of the PHR information is provided and maintained by healthcare providers. The patient has the possibility to access the EMR and mostly read through the information, but it is usually not common to have the possibility to edit or change the data in the EMR. Another type of PHRs are those fully controlled by patients, who enter and maintain their own health data. This health data can be brought over to be discussed with the healthcare practitioners during consultations, and the collaboration and interaction happen outside of the PHR. Another type is PHR platforms. They are supposed to be a mix among standalone PHRs and tethered to EMR PHR but with a distinction to be untethered with a specific healthcare provider. PHR platforms are supposed to give the patient the freedom to use the PHR independently from where s/he is receiving the treatment. PHRs are considered to have the potential to contribute to patient empowerment by implying changes in the way healthcare is delivered and giving patients the possibility of being more involved and getting more control over their care (Pagliari et al., 2007). However, their usage is still low, and the complete potential of PHRs in empowering the patients in having more control and being involved in their care hasn't been explored.

Some examples of PHR for rehabilitation are: Gammon et al. (2014) presenting an ICT-based system solution that enhanced personal health capacity. Groussard et al. (2018) and WangYue et al. (2013) that present ICT solutions which support the patient in being more involved in the rehabilitation either by having a personal application that can help only them or more cooperative systems to share with healthcare practitioners. On this topic, a project called MAGIC - Mobile Assistance for Groups and Individuals within the Community - STROKE REHABILITATION [6] has been funded by the European Union. The project is focused on: transforming the delivery of health and social care services for patients who have experienced a stroke by providing ICT-based solutions that improve the well-being of the patients and optimize the opportunity for recovery post-stroke.

Besides discussions in research, there is an advancement in commercial

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[6] http://magic-pcp.eu/

solutions. That is the case of COGNUSE[7], which presents an integrated ICT solution that can facilitate all aspects of rehabilitation management by the patient, increasing in this way her/his chances to be more involved, engaged, and empowered in her/his own rehabilitation. Such solutions are the target of analysis and further design in this thesis.

I am interested in the design of such empowering technologies and the characteristics that such technologies should have. Thus, in the following subsection, I review some characteristics for designing ICT solutions for supporting empowering practices in healthcare and rehabilitation.

How to design these technologies?

Akeel and Mundy (2019) present a unified technology-driven framework for patient empowerment. In the framework, they connect each specific outcome (he refers to them as factors) of patient empowerment with a type of technology. They argue that the integration of all of these technologies creates the right support for patient empowerment. Figure 3.1 shows their model.

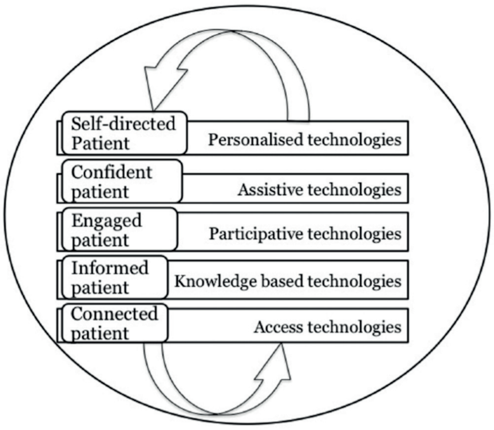

Figure 3.1: Technology framework by Akeel and Mundy (2019, p. 1279)

The framework shows that to support patient empowerment, there is a need for a technology that would enable patients to access the care data, become informed and gaining knowledge, enable their engagement in the care, supports patient's confidence, and target patient's individual needs. The framework is aligned with my findings of empowerment outcomes presented in Section 3.2: participation, understanding, control and cooperation. However, the framework lack highlighting that the patient to access, be engaged, informed, confident, and self-directed does that in relation to the healthcare practitioners in whatever setting. This is noticeable in the visualization of the framework as shown in the figure above.

Calvillo et al. (2015) instead discuss that to design technologies for patient empowerment, we should take into consideration different degrees

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[7] http://cognuse.com/

of empowerment and treat them as millstones that the technology should facilitate. This is similar to Akeel and Mundy (2019) and the discussion of patient empowerment above. This approach in technology design for patient empowerment is adequate on a meta-level of design. Interpreted based on Zimmerman and Warschausky (1998) empowerment theory that I have adopted in this thesis, they are saying that we need to design the technology to meet the empowerment outcomes. This is not wrong. However, it overlooks the design of such technologies as support for situated empowering practices that contribute to such outcomes.

Other authors that have presented a framework for designing ICT for patient empowerment are Karni et al. (2020). The authors elaborate on a set of ICT strategies for patient empowerment. The features that the technology should have involved are education, feedback to both patients and healthcare practitioners, monitoring, communication, analysis, and engagement incentives.

To facilitate sharing information between patients and healthcare practitioners, it is relevant to remember the differences in their way of communication. In this case, technologies for patient-friendly personalized language become relevant. They can support word changing in healthcare reports in order to make the reports more approachable and readable by the patients (Adnan et al., 2015).

All the design characteristics highlighted in the studies reviewed above are relevant to consider when designing empowering artifacts for patient empowerment in rehabilitation.

Technologies for patient empowerment in cognitive rehabilitation

Empirically I have studied cognitive rehabilitation as my case study for exploring empowering practices and artifacts in patient empowerment in rehabilitation. Hence, I have reviewed in this subsection technologies designed specifically for cognitive rehabilitation as a way to better understand and analyze the findings in my case.

Gaggioli et al. (2009) in their book “Advanced technologies in rehabilitation: Empowering Cognitive, Physical, Social and Communicative Skills Through Virtual Reality, Robots, Wearable Systems and Brain-computer Interfaces” have described different kinds of technologies that aim the empowerment of patients in terms of gains in functions and gains in rehabilitation outcomes. So, less focus is on the management of the rehabilitation process and on assisting the patients in taking control of her/his own rehabilitation.

However, such examples exist. That is the case of Särelä et al. (2009) who describe a new care model in home-based cardiac rehabilitation. The authors present a mobile-based system that supports the whole patient’s rehabilitation process while at home. It focuses on enhancing individual abilities through education and serves as a cooperative tool together with healthcare practitioners. Another relevant example is the one of Varnfield et al. (2011) who present a tool that can support patients in cognitive rehabilitation.

The tool is compounded by a mobile phone application serving as a platform for performing many cognitive rehabilitation activities. The mobile application is connected with clinicians who can monitor patients' progress, help set goals, and give more personalized follow-up. This shows a good example of an ICT solution that supports patient empowerment regarding the rehabilitation of specific interventions and the whole process's management.

Wentink et al. (2018) study the use of ICT in rehabilitation and the patient's willingness to use ICT. They found that people use the PC, SMARTPHONE, and Tablets in their daily life, and they would be willing to use these technologies to: have access to their health records, communicate with healthcare practitioners, and schedule appointments.

Vourganas et al. (2019) present a literature review on factors that contribute to the use of stroke rehabilitation technologies. They found that such technologies should have the following characteristics: non-intrusive, non-wearable, should enhance motivation and engagement, support an individualized approach, supporting daily activities, be cost-accessible for everyone, simple, transferable, suitable for peoples' abilities and be relevant to use. The authors found that there was no solution described in the literature that would fulfill all the characteristics.

Another relevant variable to consider is where the patient is situated. Prey et al. (2013) present a literature review on the study of patients engagement in an inpatient setting. Usually, this setting is overlooked by the patient empowerment scholars. The authors found a set of relevant interventions for patient engagement in inpatient settings, such as entertainment, generic health information delivery, patient-specific information delivery, advanced communication tools, and personalized decision support. These findings are also relevant when it comes to designing new ICT solutions for patient empowerment considering that almost all patients have their inpatient period and can make use of digital solutions during hospitalisation period.

In conclusion, the literature review presented above shows that there is a wide range of technologies for patient empowerment in healthcare, rehabilitation, and specifically for cognitive rehabilitation. While these technologies tend to contribute to different empowerment outcomes, they do so by supporting the patient individually or serving only as communication mechanisms between the patients and the healthcare practitioners. In most cases, the technology seems to be there but not fully integrated with every aspect of the empowering practices. Moreover, the studies that I presented above show that there are recommendations of how to design such technologies or characteristics of technologies for patient empowerment in rehabilitation; however, they have not been studied on empirical situations and in close relation with empowering practices as perceived and described by patients and healthcare practitioners.

3.2.3 CSCW studies in healthcare and rehabilitation

Computer Supported Cooperative Work (CSCW) is a field concerned with the design of information technologies for cooperative work. CSCW in this thesis is relevant for the analysis and the discussion of patient empowerment as a cooperative work arrangement between the patient and her/his healthcare practitioners. CSCW is a design field (Schmidt and Bannon, 1992), focused on designing adequate computer support for cooperative work, which in my study can contribute to define some design implications for empowering artifacts in rehabilitation.

CSCW research in healthcare is broad (Fitzpatrick and Ellingsen, 2013). Fitzpatrick and Ellingsen (2013) review of the literature of CSCW in healthcare presents a thorough account of the research done and future research and challenges that need to be addressed. They state that the themes discussed in CSCW in health care are: a) understanding collaborative healthcare work in relatively bounded clinical settings, as mediated by artifacts and technology, particularly the patient record and as located in space and time; b) understanding healthcare work in expanding contexts, looking at multidisciplinary team meetings and telemedical consultations, integration, and standardization, and moving care into the home; and c) finally designing systems to support healthcare workers in various contexts.

If I position this thesis in the themes described by Fitzpatrick and Ellingsen (2013), I can argue that it contributes to understanding healthcare work in expanding contexts (b) such as rehabilitation. Moreover, it opens up the discussion of changes in cooperative work arrangement and cooperative artifacts in healthcare when the patient shifts from a passive actor into an active one in her/his care. Hence, my study learns from CSCW and also contributes to it.

In CSCW research, most work has focused on studying clinicians' work and how they cooperate with one another. These studies have been done in different settings such as emergency rooms (Zhang et al., 2017; Dovigo and Redaelli, 2010; Bjørn and Hertzum, 2011; Paoletti, 2009; Kusunoki et al., 2015), shifts (Tang and Carpendale, 2007), telecare (Aanestad, 2003), etc. In the 80s Strauss and colleagues (Strauss et al., 1985) have discussed patient work. They found that patient work is either invisible or not considered work by the healthcare practitioners. The discussion about patient work continued. However, not until recently patient work and their contribution to the cooperation space with their healthcare practitioner started getting researchers attention (Bratteteig and Wagner, 2013; Blackwell et al., 2017). Nevertheless, the studies of patients' work and their role in the cooperative space of their care have been discussed mostly for cases when the patient is at home and still receiving care either by occasional encounters or by telemedicine support (e.g., (Bratteteig and Wagner, 2013)). Patient work in hospitals remains still an under-researched topic, and that is where this thesis contributes.

CSCW in rehabilitation

CSCW has paid tribute to rehabilitation, and some CSCW research has been conducted in rehabilitation settings. I conducted a literature search in 2019 regarding 'rehabilitation' in publishing venues such as the CSCW Journal, CSCW conference, and ECSCW conference. I was investigating CSCW research in rehabilitation. From the search, I retrieved 15 articles from the CSCW journal, 8 from the CSCW conference, and 3 from the ECSCW conference that were referring to rehabilitation. However, among these articles, only a limited number had rehabilitation in focus. Some of the articles described facets of the rehabilitation practices. However, none of the publications described or analyzed the practices and especially not with a perspective of empowerment. Some publications described possible interventions technologies that can be used in supporting rehabilitation practices (Bagalkot and Sokoler, 2011; Benjamin et al., 2012; Bossen and Grönvall, 2015; Mathur, 2013; Yano et al., 2000; Tang and Wang, 2015; Zhu and Carroll, 2018).

Other contributed in concepts development such as:

- "collaboration in-between" coined by Bossen and Grönvall (2015) referring to the work of those institutions where people go after a hospital stay to have some rehabilitation time before they go home. Sunnaas Rehabilitation Hospital can be considered such an institution.
- "collaborative articulation" of the rehab process defined by Bagalkot and Sokoler (2011) to describe the collaborative work that patients and their healthcare practitioners should be involved in during rehabilitation. The authors have developed a tool that assists collaborative articulation on a specific physical rehabilitation training between a patient and her/his PT.

  Similar tool that support collaborative articulation is the CARE paper presented in Sokoler et al. (2006). It has been used in the case of post-hand-surgery rehabilitation. The tool consist of Anoto Pen that is able to read paper written links and display digital content. The CARE paper offers the facilities of using a paper, and it needs to be connected to a computer to make use of the CARE paper multimedia links (ibid).
- "explicit interactions" is closely related to collaborative articulation described first in Hillgren and Linde (2006) referring to interaction techniques designed to make actions and intentions visible, understandable, and accountable (Sokoler et al., 2007).

So, work organisation studies in rehabilitation are limited in CSCW. Esepcially relevant and in line with my study is the paper of Hillgren and Linde (2006) titled "Collaborative Articulation in Healthcare Settings – Towards Increased Visibility, Negotiation and Mutual Understanding". They have studied factors that can influence patient empowerment and define collaborative articulation, increased visibility of actions, negotiation and mutual understanding as practices that will contribute to empowerment. Their findings are very relevant in my research and have similarities with my findings presented in Chapter 7.

While CSCW studies on cooperative work in rehabilitation are relevant for me to reflect later on the empowering practices for rehabilitation, CSCW as stated above is a design field and the aim is the design of computer systems that support cooperative work. I will present some CSCW work below that are focused in the design of computer support for patient involvement in her/his care in cooperation with healthcare practitioners.

Cooperative healthcare systems

In the pursue of patients digital solutions for patient involvement in her/his care, I found that the term "Personal Health Record" was mostly used in CSCW to refer to such cooperative healthcare systems to be used between patients and healthcare practitioners. So, I will shortly review the conceptualisation of PHR is CSCW.

Among the first to develop a PHR prototype and discusss its conceptualisation in CSCW were Cabitza et al. (2015). However, they call these systems InterPersonal Health Record (IPHR) as a hybrid electronic record that merges to get the typical EMR and PHR related features and contributes to enhancing relationships, communication and collaboration between citizens/patients and their healthcare practitioners. The emphasize on the *interpersonal* aimed to highlight the involvement in the management of care of both patients and healthcare providers. MEDICONA is an example of an IPHR that they develop (Cabitza and Gesso, 2014). They discussed that IPHRs should be conceptualise as a common information space (CIS) where patients and healthcare practitioners can access the information that they need regarding health management. CIS is a very important concept in CSCW. It is a conceptual framework which highlights the relationship between actors, artifacts, information, and cooperative work (Schmidt and Bannon, 1992). The aim is to provide an analytical tool that can inform developing systems that can support cooperative work (Schmidt and Bannon, 1992).

A recent and significant contribution in conceptualizing PHRs in CSCW is the work of Vassilakopoulou et al. (2019). They conceptualize PHRs as information spaces of a hybrid character. They state that "PHR can be more than a private tool, serving as CIS that straddles work and non-work contexts, bringing together participants – patients and professionals – in a collaborative relation"(Vassilakopoulou et al., 2019, p. 1016). Thus, considering PHR as personal and common information spaces that stresses the cooperative dimension of the patient doctor relations.

These perspective of PHR as hybrid information spaces where patients and healthcare practitioners are brought together is relevant in relations to the patient empowerment movement. However, the cases described such as MEDICONA (implementing the record concept which can be shared with different user types. The users have as well the possibility of electronic messaging) or MyHealth (accessing and storing personal health information and electronic exchanges between patients and healthcare providers, offering connections to several existing systems and the possibility for other application applications to connect and extend the core functionality (Vassilakopoulou et al., 2019)) and MyBook (facilitates information sharing (Vassilakopoulou et al., 2019)) show examples of PHR tools which facilitate communication, awareness through records, and collaboration based on the information shared in the common space, but not cooperation, even though cooperation is an important element in healthcare and is essential when it comes to empowering the patients (quoted from Carcani et al. (2020)).

3.2.4 PD studies with people with cognitive impairments

In Section 3.1.2, I reflected on the empowerment outcomes in co-design. I consider these empowerment outcomes when exploring the empowering practices and empowering artifacts. I have reviewed what previous research has been done in PD in co-design with MACI people and what are some of the empowering practices and artifacts described.

While there is extensive research on conducting PD with people with cognitive impairments, research cases with MACI people are almost not present at all.

Among people with cognitive impairments the groups that have been mostly researched are people with dementia, aphasia, amnesia, or in general, in the old adults' population. A set of workshops' has been organized in conferences discussing the practices for involving people with cognitive impairments in co-design (Hendriks et al., 2015, 2014; Slegers et al., 2013, 2014). Moreover, a considerable number of papers had been published ((Lindsay et al., 2012; McGrenere et al., 2002; Moffatt et al., 2004; Hendriks et al., 2015, 2014, 2013)). Overall, the papers dedicated to PD with people with cognitive impairments describe projects where people with cognitive impairments have been involved in co-design within the group and with the designer. In some cases, healthcare practitioners or family members have also been involved, but only as a support for the person with cognitive impairments and not representing themselves. In other cases, healthcare practitioners have been involved in co-design as proxies of people with cognitive impairments (Galliers et al., 2012; Colonius et al., 2010; Borges et al., 2013).

For mild cognitive impairments, extensive research has been done with old adults or people with intellectual disabilities. However, little research has been conducted specifically on patients suffering from mild cognitive impairments that are not related to age but to damage in the brain acquired at some point in life. The closes example to my study is the study of Nakarada-Kordic et al. (2017), where people with psychosis are involved in participatory design. While psychosis can be a consequence of ABI, it is not always related to an ABI. Thus, the category of people studied does not fit exactly in the definition of MACI patients that I presented in Chapter 2.

Augstein et al. (2016) is another example where a study of designing an interactive tabletop for rehabilitation for people after an ABI is presented. They have conducted a PD study. However, they have involved in co-design rehabilitation specialists as proxies of people with ABI.

More research has been conducted with people that had a stroke. Balaam et al. (2010) and Threatt et al. (2014) have described some cases of involvement of stroke patients in the design process. However, this involvement is mostly in terms of interviews and observations and further during testing. The design is handled either by the designers or designers and clinicians together. The involvement of clinicians in design is as well described in Faria and Badia (2015). Instead, Magnusson et al. (2017) describe a case where stroke patients are involved in focus groups and as well in co-design workshops where brainstorming and body-storming techniques are used.

To learn from PD practices with other groups that share similarities in symptoms with MACI patients I conducted a systematic literature review on PD studies with people with cognitive impairments. In detail, the process of searching, selecting, and reviewing the articles is presented in Chapter 5 where I present my methods and my research activities. Instead, findings of such literature review are presented in Carcani and Holone (2020, p. 5-6) (included in the thesis as Paper III) where I have listed guidlines for conducted PD with people with cognitive impairment based on previous literature. Inspired by Hendriks et al. (2013) similar literature review conducted a few years earlier, I have grouped the guidelines in the following categories: Preparation, Tools, Facilitator, Techniques, Participants, and Analysis. The list of guidelines is included in Paper III in this thesis in pages 5-6 of the paper.

3.3 Putting things together: Empowerment in this thesis

Empowerment is the main concept investigated and discussed in this thesis. Empowerment has been studied in two contexts: co-design within a PD approach and rehabilitation. The co-design process has been used to investigate empowerment in rehabilitation and the co-design process itself.

Empowerment has had different definitions that I have presented in 3.1. In this thesis, the empowerment theory by Zimmerman and Warschausky (1998) makes the main understanding of empowerment. They consider empowerment as a multi-level and multi-dimensional construct. The levels are: individual, organization, and community (previously presented in Zimmerman and Rappaport (1988)). The dimensions of empowerment are: outcomes, practices, and values. The levels and dimensions are interrelated and influence each other. I discussed above that Melander Wikman and Fältholm (2006) based on the work of Ghaye (2008) includes another empowerment level, the group/team level by extending the three levels by Zimmerman and Warschausky (1998). I concur with this addition, and I find the group/team level relevant for the study of empowerment in this thesis.

In the discussion of empowerment in general and then specifically in co-design and rehabilitation, I found in the literature that a very important role in empowerment play artifacts[8], being these tangible or digital artifacts.

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[8] Artifact comes from Italian artefatto, from Latin arte "by skill" and factum "thing made," from facere "to make, do" and stands for "artificial production, anything made or modified by human

Tools used in PD or paper documents or EMR in healthcare contribute to enabling empowerment outcomes. I refer to them as "empowering artifacts," including any type of artifact that can support or enable empowering practices and empowerment outcomes and values. Empowering artifacts can influence and can be influenced by empowering practices, and their design and use contributes to empowerment expected outcomes.

Thus, in this thesis, I consider the empowering artifacts as another dimension of empowerment that should be considered in research in empowerment. Similarly to the other dimensions, empowering artifacts can be studied in each of the levels. Empowering artifacts can contribute to individual empowerment. An example are those workplace technologies that aimed to increase a worker's efficiency in doing her/his individual tasks. Empowering artifacts can contribute to empowerment in groups/teams. Groupware systems are an example. Empowering artifacts also contribute on the organizational or community level. An example are organization-wide systems or systems used inter-organizationally. Another case are the community-based systems that empower an individual at the community level.

Based on the discussion and arguments presented above and the additions to the Zimmerman and Warschausky (1998) empowerment theory I tried to visualize the empowerment theory as shown in Figure 3.2

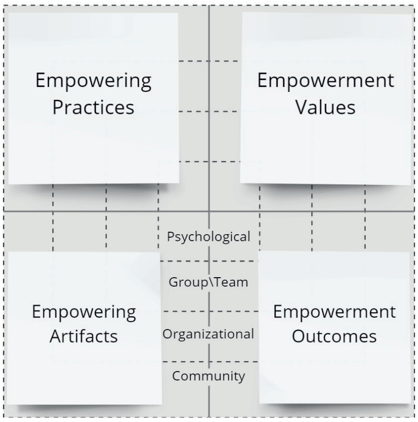

Figure 3.2: My own illustration of empowerment theory as a multi-dimensional and multi-level construct - a visualisation and extended version of the work of Zimmerman and Warschausky (1998)

In this thesis, I am concerned about empowering practices and the design of empowering artifacts at the group/team level to achieve empowerment outcomes at the individual level. This means that for patient empowerment in rehabilitation, the aim is two achieve empowerment outcomes for the patients. Instead, I investigate empowering practices and artifacts on the group level where the patient and her/his healthcare practitioners together contribute to the patient empowerment. For MACI people empowerment in PD of cooperative

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art." from https://www.etymonline.com/word/artifact?ref=etymonline_crossreference#etymonline_v_17051 artifacts, the empowerment outcomes aim MACI people's empowerment in co-design when they are involved in co-design with the designer/researcher and their healthcare practitioners. Instead, the empowering practices and artifacts will be investigated in terms of the co-design sessions organization and structuring. I grounded my understanding of empowerment outcomes in the literature.

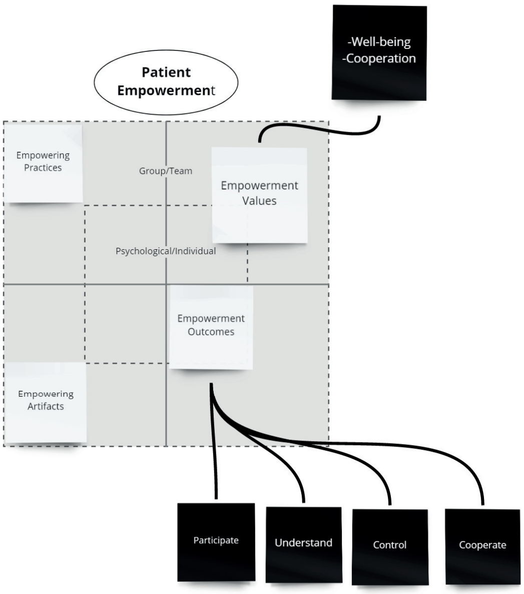


Figure 3.3: Patient empowerment portrayed in the empowerment theory matrix

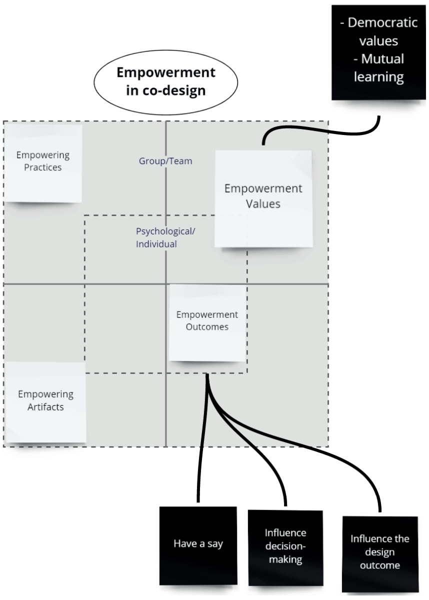


Figure 3.4: Empowerment in co-design portrayed in the empowerment theory matrix

Patient empowerment outcomes in rehabilitation are considered: the patient *participates* in the decision-making regarding her/his rehabilitation process and treatment, the patient *understands* the process, and the patient *controls* of their rehabilitation. Another empowerment outcome for the patient and her/his healthcare practitioners is to *cooperate* in the care process. This is an outcome that sits on both individual and group/team levels. Moreover, patient empowerment in rehabilitation has the value of patients' well-being, which is the same on the individual and group/team level.

Participants empowerment outcomes in co-design are considered: enabling the MACI people during the design process to *have a say*, *influence decision-making* and the *influence the outcome* of the co-design process. The participants that I am aiming to achieve empowerment outcomes for are MACI people when they are involved in co-design with their healthcare practitioners that differences in power surface. In co-design, the empowerment discourse is built on a democratic value in the design and immersion of technologies in people's life.

In Figure 3.3 and Figure 3.4, I have adapted the visualization of the empowerment theory to the two contexts that I study, the levels I focus and what empowerment values and outcomes I consider in this context. The literature review showed a gap in studies of empowering practices and artifacts in patient empowerment in rehabilitation and PD with MACI people. With this theoretical background, I moved further into my empirical investigations.

CHAPTER 4

ANALYTICAL CONCEPTS

> "Scientists have become the
> bearers of the torch of discovery
> in our quest for knowledge."
>
> *Stephen Hawking*

Literature and some of the concepts relevant in the analysis and discussion of empowering practices and empowering artifacts in co-design and patient empowerment in rehabilitation, have been listed and presented in this chapter.

In the previous chapter, I found that cooperation between a patient and her/his healthcare practitioners is an empowerment outcome for patient empowerment. This empowerment outcome is even more relevant in rehabilitation, where the cooperation established can also contribute to better rehabilitation outcomes. Cooperation between patients and the multidisciplinary team is an important part of the rehabilitation models, and cooperative practices are already in place in rehabilitation settings. Hence, I investigated the current cooperation practices at Sunnaas Rehabilitation Hospital and also studied future improvements that would enhance patient empowerment with patients and healthcare practitioners. I draw my analysis and discussion of empowering practices and implications for the design of empowering artifacts in Computer Supported Cooperative Work (CSCW) literature and concepts. I argue in the following section why CSCW as a research field is suitable in my research, and I described those CSCW concepts that have been relevant in my study.

I draw my analysis of empowering practices and empowering artifacts in co-design with people with Mild Acquired Cognitive Impairments (MACI) in Participatory Design (PD) literature and concepts.

4.1 CSCW

The term Computer-Supported Cooperative work was coined by Irene Grief and Paul Cashman in a workshop in 1984 in discussing how people work and what could be technologies role in the work environment. While this was the first incentive and use of the concept, it was in the few years after that, that researchers shaped the research field as we know it today (Bannon and Schmidt, 1989; Schmidt and Bannon, 1992; Grudin, 1994). It was defined by Bannon and Schmidt (1989, p. 5) as "an endeavor to understand the nature and characteristics of cooperative work to design adequate computer-based technologies". They highlighted the interest in this special type of work, cooperative work, and positioned the field as a design field. Schmidt and Bannon (1992, p. 11) state:

> "CSCW is basically a design oriented research area. This is the common ground. Enter, and you must change."

Historically, at the root of CSCW stand workplace transformations toward embracing a more socio-technical perspective (Trist, 1981). In the industrialization period after WWII, researchers started showing more interest in how work was organized and how technologies were and could influence and contribute to workplace transformations (Grudin, 1994). Special attention was given to the social and cooperative nature of work (Greenbaum and Kensing, 2012). CSCW was that field that started being concerned about investigating the social and organizational aspects of IT used to support cooperation (Grudin, 1994).

While CSCW is a design field, a significant part of CSCW are the so called workplace studies. Luff et al. (2000) and Heath et al. (2000) have described workplace studies as concerned with the practical accomplishment of workplace activities and how tools and technologies feature in work and interaction within organizational environments. Workplace studies position practical action at the center of analysis and pursue a naturalistic "thick description" of the workplace at hand and the complex relationship among co-workers and in relation to technology. Schmidt (2000) argues the criticality of workplace studies in CSCW not only in designing better technology support for cooperative work, but also in conceptualising cooperative work and uncovering those invisible, tacit and unnoticed elements of cooperative relations which might have a huge impact on how people cooperate. Ethnography is a common methodology in workplace studies. Luff et al. (2000) and Heath et al. (2000) provide an account of relevant research in workplace studies in CSCW. Furthermore, Heath and Luff have discussed workplace studies specifically in healthcare and acute hospital wards (Heath et al., 2003).

At start, CSCW was focused on group work. However, the focus only on group work and the association with "groupware" technologies was considered by Bannon and Schmidt (1989) as a narrow approach. Thus, they proposed a broader approach to the field by making the locus of research on cooperative work the "ensembles" representing either people, groups, or organizations that enter into a cooperative work relationship with one another.

The short presentation of CSCW history and focus as a field is relevant to argue why I position my study in CSCW. One of the empowerment outcomes of patient empowerment was cooperation between patients and healthcare practitioners. The cooperation should enable the patient to participate in decision-making and influence her/his own treatment, understand the treatment plan and gain the ability to control her/his own treatment. Hence, empowering practices in patient empowerment should be cooperative practices that enable the empowerment outcomes of participation, understanding, and control for the patients.

In rehabilitation, as described in Chapter 2, there are currently cooperative practices in place that support patient involvement in her/his rehabilitation. This is not randomly the case in acute wards. To define empowering practices for patient empowerment in rehabilitation, I critically analyze the current cooperative practices in rehabilitation and also investigate what needs to be improved. Moreover, I am concerned about design implications for empowering artifacts that support empowerment outcomes. The empowering artifacts should be cooperative artifacts that can facilitate cooperation. So, I study cooperative work between a patient and her/his healthcare practitioners and aim to design cooperative artifacts. This is very much in line with CSCW. So on Schmidt and Bannon (1992) words, I do not need to "change" as my research is already within the frame drawn by them on the CSCW field.

Moreover, I argue that the multidisciplinary team of healthcare practitioners and the patient represent one "ensemble", where each party should have its cluster of tasks. In CSCW in healthcare, it has mainly been studied healthcare practitioners' work (Fitzpatrick and Ellingsen, 2013). However, what makes my study different is that the patient is considered part of the cooperative work in the ensemble created for her/his care. While the patient position has been recognized in the care process, their work contribution has either been invisible to healthcare practitioners or has not been considered work (Strauss et al., 1985). Bratteteig and Wagner (2013) study the work in homecare. They found that, at home, some of the workload is redistributed from healthcare practitioners to patients or their kin. While patient empowerment is relevant at home, the question that I raise is how to start this empowerment earlier and how to create the possibility to redistribute the tasks even when the patient is at care institutions.

In summary, I build on CSCW to understand cooperation and analyze the requirements for improving this cooperation in rehabilitation and then re-construct these pieces of knowledge as empowering practices and design implications for empowering artifacts that support patient empowerment. The aim is to make the patient visible and negotiate with them how to redistribute some part of the work.

I present below an overview of those CSCW concepts that have been relevant in my analysis and contribute to articulate my findings. In presenting the concepts, I have referred to seminal and classic papers where these concepts have been defined, discussed, or problematized.

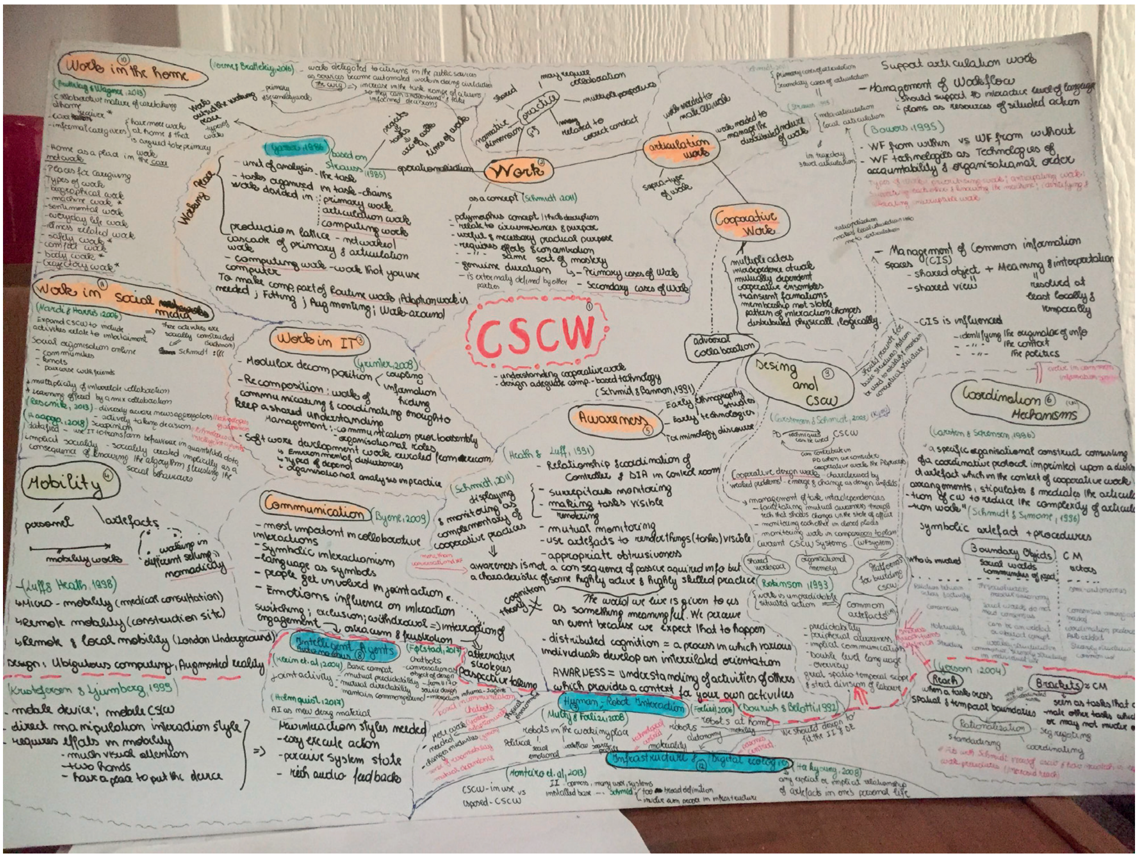


Figure 4.1: My CSCW Map

My view on the CSCW field

During my PhD studies, I took the course "Computer Supported Cooperative Work" at the University of Oslo. In this course, the students were presented with an overview of the field, concepts, and relevant theories. The course was beneficial in expanding my knowledge in the CSCW field. As part of this course, we were tasked to create a map of the field based on our understanding of the course's extended literature.

My map is shown in Figure 4.1, and I include it in this thesis because I always get back to this map and try to position myself in one of the concepts and domains when I want to investigate a specific aspect of a cooperative work arrangement. Moreover, this map has helped me in my reflection for writing the papers and presenting and discussing the CSCW concepts in the upcoming subsections.

4.1.1 Cooperative Work

CSCW is concerned with a specific kind of human work, that is, cooperative work (Bannon and Schmidt, 1989). Before explaining what comprises cooperative work, I initially describe how work as a concept and its organization has been conceptualized in CSCW.

Schmidt (2011b, p. 376) in his analysis of the concept of work in CSCW, states that in ordinary language, work is used to represent:

> "the given activity that serves a useful or necessary practical purpose and that it, therefore, requires effort and concentration and presumes mastery of all sorts and technicalities."

He adds that work is a "polymorphous" concept that can only be described and not pertain to a single definition. We as researchers can contribute to research by trying to untangle and analyze how work is done and not on what it consists of.

This conceptualization is relevant in arguing how empowering the patient in her/his care means that there is a need: 1) to recognize the patient's role in her/his care as work and 2) introduce practices that require patient work. These should be activities that serve useful or necessary practical purposes, require the patient's effort and concentration, and consider the patient's expertise in her/his condition. This does not mean overwhelming patients or making them feel the only responsible, but making visible their part of work in a cooperative work arrangement with the healthcare practitioners.

Anhelm Strauss and colleagues have a major contribution in describing how work is organized (Strauss, 1985). Strauss (1985, p. 4) starts with a "project", that he exemplifies as "inventing a new computer model, building a house, getting a voluntary organization off the ground, etc". Further, he adds that in a project, a course of actions is involved. An action is made up of a multitude of tasks sequentially or simultaneously done over time and divided up according to actors (persons, classes of persons, departments, or another organizational unit). An action can have many activities. An activity is a cluster of tasks. Strauss conceptualizes the totality of tasks in a project as "the arc of work". A bundle of projects with their "arc of work" make up a "line of work".

This understanding of the arc of work as compounded by tasks grouped in task clusters is relevant when analyzing the work practices in rehabilitation, how the work is organized, and what are the task or task clusters to be changed, added, and redistributed.

As stated above, CSCW is concerned with a special type of work that is cooperative work. Historically, cooperative work emerged somewhere in the first half of the 19th century as the type of work involving multiple actors. It was later defined by Marx (1867) as "multiple individuals working together deliberately in the same production process or in different but connected production processes" (as cited in Bannon and Schmidt (1989, p. 13). This highlights the interdependence at work as the main characteristic of cooperative work. Work is a social state (Schmidt and Bannon, 1992), and people engage in cooperative work when they are mutually dependent on each other to get the job done (Schmidt, 2011a). However, the mutual dependency is based not only on sharing resources but also on positively counting on each other's work as the only way to complete tasks or projects.

Cooperative work as a term does not imply a positive connotation related to happy cooperation among ensembles. Conflicts can exist, but the ensembles need to find ways to neutralize them and work together due to technical necessities or economic needs in certain work environments. In Marx's work, cooperative work has been studied in conflicting power relations in industrial environments. However, Schmidt and Bannon (1992, p. 16) state that:

> "the concept of cooperative work should not be taken to imply a particular degree of participation or self-determination on the part of the workers, nor a particularly democratic management style."

This does not mean that the degree of participation and democracy in the workplace has not been discussed in CSCW. Nevertheless, it does not define the field.

Moreover, not every social encounter at work is considered cooperative work. Cooperative work is associated with work processes that contribute to producing a particular product or type of products (this can also be an abstract conceptualization or framework) (Schmidt, 1990).

In rehabilitation, patients and healthcare practitioners should cooperate. For example, the Occupational Therapist (OT) defines a memorization technique relevant for the patient. The patient should be engaged in learning the technique and try it out on her/his own. Thus, the cooperation for them involves interrelated tasks dependent on one another to achieve the common goal: patient learning the technique.

Moreover, the OT is not the only one involved in cooperative work. The OT may need to cooperate with the Psychologist because the patient needs some psychology sessions to manage stress when not remembering things. The OT, the Psychologist, and the patient should be responsible for individual and joint clusters of tasks in rehabilitation. Their work is dependent on the work of others. Not always are they willing to cooperate but do so because they have a common goal, the improvement of the patient condition or compensation for the condition. So, rehabilitation work is cooperative work as defined in CSCW, and the ensemble is the multidisciplinary team of healthcare practitioners and the patient.

I found that cooperation between the patient and her/his healthcare practitioners is an empowerment outcome in patient empowerment. Thus, cooperative practices in healthcare are empowering practices that will contribute to empowerment outcomes.

To design technologies that support cooperative work, we should initially understand the social system of work compounded by the functional system related to the "work organization" in terms of tasks and tasks lattice, and the social system of work as an arena of a human factors called the "social organization" (Schmidt, 1990).

Analyzing cooperative work from the "work organization" perspective and "social organization" perspective aids me to understand and co-design with them the cooperation between a patient and her/his healthcare practitioners in the pursuit of patient empowerment. This means that to discuss cooperation, patients and healthcare practitioners should revise the way work is organized

- so tasks, tasks clusters, and the way people become accountable for their assigned tasks. Moreover, they should discuss how the tasks are allocated. Strauss et al. (1985) describe different modes of task allocation: imposed, requested, assumed without request or command, delegated or proffered, accepted or rejected, and negotiated.

The understanding of cooperative work from CSCW has been useful for the analysis of cooperation in rehabilitation from a patient empowerment perspective and further to propose such practices to empower patients. Moreover, considering the complexity of cooperation in rehabilitation, I have also contributed to the "cooperative work" body of literature by analyzing this new setting. In the next subsections, I present some of the most discussed concepts in CSCW that have contributed as analytical concepts in the findings presented in this thesis.

4.1.2 Articulation Work

In defining the interrelations in the totality of actions and tasks making a project and the actors that will work in those specific actions or tasks, a division of labor is needed. Since the plurality of tasks and actors' relations to tasks are not automatically articulated, actors must do that too and often in complex ways. Strauss (1985) calls the work of doing this "articulation work", defined as some kind of supra work aiming to facilitate the division of labor. Articulation work is an important part of cooperative work.

'Articulation work' is the effort of coordinating tasks and responsibilities between distributed collaborators, and can be lessened by developing divisions of work, routines, conventions, and by the use of artifacts such as schedules, plans, and schema (Schmidt and Bannon, 1992). Articulation work involves these activities:

- defining what tasks and clusters of tasks make an arc of work and how they are interrelated
- defining the expertise of workers
- mapping workers expertise with the tasks and task clusters

In clarifying what articulation work is in cooperative work, Schmidt writes that "articulation work is work to make work work" (Schmidt, 2002a, p. 19). He argues that articulation work is itself a cooperative work effort.

Articulation work is conceptualized as necessary at different levels. Strauss et al. (1985)) define articulation work levels that variate from the upper management coordination activities to the coordination needed in completing a specific task. Each person may also be involved in lower-order operational articulation work.

Meanwhile, Schmidt (2011a) defines two types of articulation work. He distinguishes among the first order articulation work as "the activities of mobilization and deployment — the very constitution and reconstruction of the cooperative work arrangement" and secondary articulation work as "the activities through which the activities of the cooperative work arrangement, as already constituted, are coordinated and integrated". Oskarsen (2018) has argued that the first articulation work is the process where the cooperation is established, and work is divided. Instead, the second type of articulation work is recurring as long as there is a cooperative work arrangement. Articulation work can also span organizational boundaries outside of the local work arrangement (Færgemann et al., 2005).

Articulation work is relevant for this thesis when analyzing the organization of work in the rehabilitation process, how the treatment is defined, and how the work continues to be distributed once the interventions have started. Moreover, applying the concept of articulation work to reflect on the patient role in rehabilitation contributes to elicit empowering practices and how to better design cooperative artifacts that support patient empowerment in rehabilitation. Moreover, when reviewing CSCW studies in rehabilitation, "collaborative articulation" (Bagalkot and Sokoler, 2011) is one of the concepts closely related to work organization in rehabilitation. I reflect on such concept and contribute with an additional perspective rooted in my findings.

4.1.3 Cooperative Artifacts

A very important part of CSCW is the CS - computer support. Different terms have been used in CSCW to describe different types of "computer support". Not always the tools used to support cooperative work have been computers or digital solutions. Even a paper document such as "the bug report form" or the "CEDAC board" described in Carstensen and Sørensen (1996) present the case of artifacts used to support cooperation and coordination at work.

In this thesis, I use "cooperative artifact" as an umbrella term to refer to any type of artifact that is used to facilitate cooperation (as in Bjerrum and Bødker (2003); Pan (2016); Cabitza and Mattozzi (2017) where no definition is provided, but the concept is used similarly).

In CSCW, two terms have been widely used to refer to artifacts that support cooperative work: coordinative artifacts by Bardram and Bossen (2005) and computational artifacts by Suchman (2007).

Bardram and Bossen (2005, p. 168) describe coordinative artifacts as "...whiteboards, plans, schemes, procedures and templates designed to provide order to and coordinate the multiple work processes are present at the hospital ward...". There is no clearly stated definition given in the paper, but this is the one where the authors explain what they mean. From my interpretation of the concept, it seems that the focus is mostly on coordination. However, Bardram, in a new paper with Houben discussing collaborative affordances, in the abstract state "Artifacts and tools which possess such Collaborative Affordances within a socio-cultural frame, thus form a web of interrelated cooperative artifacts (Bardram and Bossen 2005b)" (Bardram and Houben, 2018). Hence, they state "cooperative artifacts" and refer to a paper where the "coordinative artifacts" are highlighted - Bardram and Bossen (2005).

“Computational artefact” was coined by Suchman (2007, p.1) and “refer to artefacts that follow the dynamics of work practices rather than being merely a tool in the workplace. Computational artefacts highlight the relevance of the context in which the material or digital artifacts are given mining and used for a purpose”. Schmidt and Bansler (2016, p. 31) in their paper regarding computational artifacts state that "artifacts are designed to react in step with the activities in which they are used, to be incorporated in sophisticated semiotic practices, and to exhibit functional unity irrespective of its shifting internal constitution".

Hence, in this thesis, I use cooperative artifact(s) to refer to artifacts that support coordination when needed and which serve and get meaning in a specific context.

In CSCW literature, different types of cooperative artifacts have been studied. The different types of artifacts have helped me to reflect on what design characteristics should cooperative artifacts for patient empowerment in rehabilitation have.

My aim here is not to provide a review of all the artifacts but highlight those that have helped me analyze the cooperation and need for cooperative artifacts for supporting patient empowerment in rehabilitation. I discuss these in the next subsection.

Coordination Mechanisms and Boundary Objects

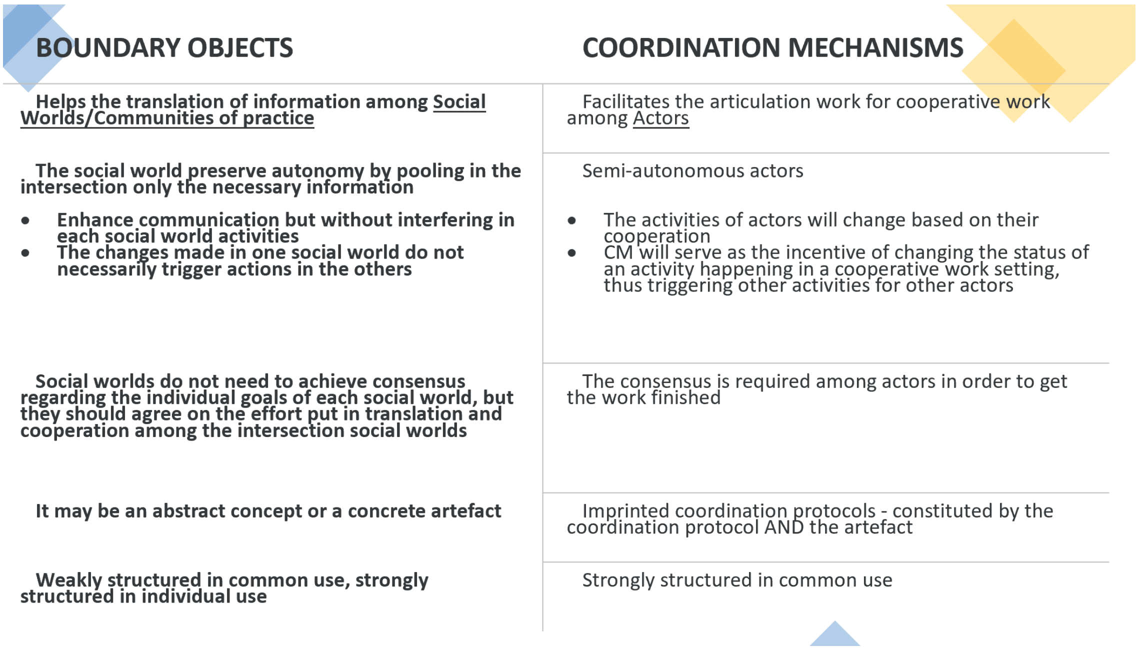
When I started discussing the design of the cooperative artifact for patient empowerment in rehabilitation at the beginning of my study, I became aware that the cooperative artifact could play different roles. This depended on where the patient was in her/his rehabilitation journey. This became more visible once I emerged more in the field and started building empirical knowledge. Two relevant concepts that have helped me in the analysis and reflection for design implications for cooperative artifacts for patient empowerment in rehabilitation are: boundary objects and coordination mechanisms. Once emerging in the literature on both concepts, I found that they were used loosely in some cases, and it was challenging for me to draw a line between them.

Thus, I conducted a systematic literature review of the definition of both concepts and how they had been used in the literature. I published the results of my review in Paper VII (Çarçani and Holone, 2019) included in this thesis.

Schmidt and Simonee (1996, p. 180) defined coordination mechanisms as:

> "a specific organizational construct, consisting of a coordinative protocol imprinted upon a distinct artifact, which, in the context of a certain cooperative work arrangement, stipulates and mediates the articulation of cooperative work to reduce the complexity of articulation work of that arrangement."

By definition, it is noticeable that the concept of the coordination mechanism describes material artifacts. This approach has been considered narrow by Bossen (2002), who emphasizes that organizational structures and divisions of labor also facilitate coordination of work since they explicate who does what and when. Thus, Bossen uses the term immaterial mechanisms of interaction for these other constructs, which facilitate articulation of cooperative work. Schmidt (2011a) in his book involves a section on revising coordination mechanisms concept. He argues that the concept of coordination mechanisms after its definition was being used loosely. Thus, he and colleagues considered it relevant to make a coordination mechanism tightly coupled with a coordination protocol on a one-to-one relation. A cooperative work arrangement could have many coordination mechanisms. Schmidt and Wagner (2001, p. 385) have described as 'ordering systems' clusters of interrelated coordinative practices and artifacts for specific purposes.



BOUNDARY OBJECTS	**COORDINATION MECHANISMS**
Helps the translation of information among Social Worlds/Communities of practice	Facilitates the articulation work for cooperative work among Actors
The social world preserve autonomy by pooling in the intersection only the necessary information • **Enhance communication but without interfering in each social world activities** • **The changes made in one social world do not necessarily trigger actions in the others**	Semi-autonomous actors • The activities of actors will change based on their cooperation • CM will serve as the incentive of changing the status of an activity happening in a cooperative work setting, thus triggering other activities for other actors
Social worlds do not need to achieve consensus regarding the individual goals of each social world, but they should agree on the effort put in translation and cooperation among the intersection social worlds	The consensus is required among actors in order to get the work finished
It may be an abstract concept or a concrete artefact	Imprinted coordination protocols - constituted by the coordination protocol AND the artefact
Weakly structured in common use, strongly structured in individual use	Strongly structured in common use

Figure 4.2: Boundary Objects vd Coordination Mechanisms

Boundary objects was coined by Star and Griesemer (1989). Boundary objects are considered artifacts or abstract concepts that stand between two different social worlds, and can be useful for both without infringing one another's autonomy. They are different from the previously presented artifacts because they do not refer only to material artifacts and are used in between social worlds that are not dependent on each other.

I concluded in a list of factors that characterize each concept and should be considered when deciding to use either one or the other concept. I summarised the results in a table where novice researcher in the field could find it easy to reflect on the similarities and differences of the concepts and use them in a correct way. I include the table in Figure 4.2. In the figure from top to bottom the rows describe in each of the concepts: Who is involved, the relation between actors and activities enabled, the necessity to achieve consensus or not, materiality, and structure.

As seen in the picture, boundary objects can be abstract concepts of concrete artifacts. I refer to boundary objects as concrete artifacts, and I return to both types of artifacts when I discuss the design implications for designing a cooperative artifact that support patient empowerment beyond one rehabilitation setting. I discuss characteristics of which artifact prevail when a patient goes from one rehabilitation setting to another and the people involved in her/his care change.

4.1.4 Awareness

Awareness is another concept closely related to cooperative work and extensively studied in CSCW. The first studies of awareness were the reports from the London Underground control room by Heath and Luff (1992) describing and analyzing the way the Controller and the Divisional Information Assistant (DIA) in the room coordinated with one another. The authors found that to make possible coordination, both actors were displaying their activities to the other and monitoring each other's activities. Both activities were conducted in a natural way without the two interrupting the work of each other.

Based on distributed cognition theory, the world is presented to people as something meaningful, and we perceive things based on our expectation of what will happen. Distributed cognition is the process in which various individuals develop an interrelated orientation. Displaying and monitoring activities help people make sense of each other's activities and adapt their own behavior to that. While Heath and Luff (1992) did not use the term awareness in their paper, their work stands in the roots of the awareness discussion in CSCW.

A widely used definition of awareness comes from Dourish and Bellotti (1992, p. 107) which state that awareness is "understanding of activities of others which provides a context for your own activity", similar to what Heath and Luff (1992) discussed in their paper.

Heath et al. (2002) argue that awareness does not mean simply rendering activities and events selectivity visible, which may be of relevance to others, but also encourages these others to undertake actions that are critical to the successful accomplishment of their own activities.

Even though awareness is a relevant concept in CSCW, Schmidt (2002b) argues that there is a lack of a clear definition of awareness. Schmidt also argues that displaying and monitoring are complementary to cooperative activities, and awareness is not a consequence of passively acquired info but a characteristic of some highly active and highly skilled practice. So, the information is not just displayed, but the other person is actively paying attention to it. Then, based on the understanding that s/he has of the cooperative work and the cooperative space makes sense of the activity in relation to her/his own work and can change her/his own behavior.

While the debate on the concept of awareness in CSCW continues (Schmidt and Randall, 2016; Schmidt, 2016; Tenenberg et al., 2016; Gross, 2013; Bardram and Hansen, 2010), it goes beyond this thesis's scope to focus on the development of concept not only for awareness but also for cooperative work, articulation work, and cooperative artifacts.

In this thesis, awareness is relevant in analyzing the relationship between patients and healthcare practitioners with the aim of cooperation for patient empowerment.

In Chapter 2, when presenting psychological empowerment, I also mentioned critical awareness, defined by Zimmerman (1995, p. 589) as "*one's knowledge of how to acquire those resources and the skill to manage the resources once they are obtained"*. So, what Zimmerman is saying is that critical awareness means knowing where you can obtain the resources you need and having the right skills to make use of the resources for yourself. Even though expressed in other words, the definitions of awareness in both fields refer to an ability to make sense of your surroundings and use that for your own benefit. The difference is that awareness in CSCW is transactional in displaying and monitoring activities and using distributed cognition to make sense of these. It is also active and dynamic. You give and receive. Instead in empowerment is individual as related to own interest.

In patient and healthcare practitioners encounters, often the healthcare practitioner does her/his reasoning and gives some suggestions to the patient. The reasoning process is neither made visible to the patient nor overseen by the patient who expects to receive a correct answer from the healthcare practitioner without understanding its reasoning. Highlighting and reflecting on awareness in the cooperation between patients and healthcare practitioners exposes such a situation. In this thesis, reflecting on awareness and the early work of Heath and Luff in the London Underground, has contributed to understand patients' current needs for empowerment and define empowering practices. Considering and discussing awareness in patients' and healthcare practitioners' cooperation has not been common in the literature. I discuss how the cooperation patient-healthcare practitioners for empowering the patient in rehabilitation presents a different situation of awareness from the DIA and controller in the London Underground case.

4.1.5 Negotiation

Negotiation derives from Latin. It can be literally translated as neg - "not" + otium "ease, leisure". In the 15th century was adapted to take on the meaning "doing business", and was later generalized to mean "bargaining about anything"[1].

It is defined in the Cambridge Dictionary "as the process of discussing something with someone in order to reach an agreement with them, or the discussions themselves "[2].

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[1] https://www.etymonline.com/word/negotiation

[2] https://dictionary.cambridge.org/dictionary/english/negotiation

Negotiation is a concept that is widely used in CSCW. When I presented cooperative work above, I also mentioned that cooperative ensembles and cooperative work is not static. This is influenced by changes in the cooperation needs and the deviations from plans in situated actions (Suchman, 1987). This brings into the picture the need for negotiations.

The dynamic and contradictory demands posed on a social system of work by the environment require that task allocation and articulation are renegotiated more or less continuously (Schmidt and Bannon, 1992). Thus, CSCW systems should consider the negotiation between cooperative actors and allow them to negotiate task allocation and articulation freely.

In cooperative work, people share information. However, sharing information does not create the necessary environment for cooperation. There is a need for interpreting the shared information in order to achieve a shared meaning. This is challenging without direct access to the situation in which the information was created. Schmidt and Bannon (1992, p. 28) state that:

> "At the level of the objects themselves, shareability may not be a problem, but in terms of their interpretation, the actors must attempt to jointly construct a common information space which goes beyond their individual personal information spaces."

Common Information Space is a very relevant concept in CSCW. Common Information Space (CIS) "encompasses artifacts that are accessible to a cooperative ensemble as well as the meaning attributed to these artifacts by the actors" (Schmidt and Bannon, 1992, p. 28). The artifacts and their meanings need to be negotiated. Negotiation is discussed closely within CISs.

To co-construct CISs requires negotiation between multiple actors. In face-to-face interactions, cooperative actors can easily negotiate a shared understanding of what is said and written and the boundary of the common information space. However, the negotiation should be made visible so people who join the CIS can later retrieve meaning from the remains of the interaction.

Munier et al. (2000) states that there is no universal negotiation model because negotiations are influenced by many parameters depending on the culture of negotiation, the language of negotiation, the field of negotiation, and the media of communication. Other factors, such as power relations, directly influence negotiations. Some tools called NSS (Negotiation Support Systems) have been developed, which combine communication, computing, and decision support techniques to assist people in their negotiation tasks. However, they do not have the flexibility to be adapted to any situation of negotiation.

Munier et al. (2000) proposes a model that integrates three different parts of negotiation mechanisms: data structures to be exchanged between agents (information language), communication protocols between actors (information exchange protocols), and actors behaviors in relation to the negotiator's acts (tactics). This allows different forms of negotiation based on the communication protocol. It also provides the possibility for synchronous and asynchronous negotiation.

They see negotiations as a transactional speech act having a beginning and an end and respecting certain criteria. An example of a negotiation protocol they take is turn-taking, meaning that someone earns the right to make a decision if it has initially earned the right to speak. However, negotiations are not influenced only by language and set protocols but also by strategies and policies implemented to coordinate several negotiations. This can be influenced by context or other tactics such as reacting to others' negotiations or coordinating different negotiations. This knowledge is very relevant in CSCW in conceptualizing Information and Communication Technologies (ICTs) that can support negotiations in CISs.

Empowering patients in managing their care process aims for an increase in well-being. However, not all patients are ready to take over tasks. Their abilities and willingness will variate. On the other side, we might want to make revolutionary changes in the way care is delivered, but without healthcare practitioners engaged in the process, the change will be opposed and difficult to happen. There is where negotiation becomes relevant in the cooperation between patients and healthcare practitioners. In this thesis, understanding the negotiation has contributed to making sense of the types of negotiations relevant between patients and healthcare practitioners. Additionally, it represents a relevant concept when analyzing how to design cooperative artifacts for patient empowerment in rehabilitation.

Moreover, negotiation is a concept used in co-design when it comes to the negotiation of values between different stakeholders (Iversen et al., 2012). I have discussed the necessity to enable negotiations in the co-design sessions where cooperative artifacts are being designed.

Hence, the concept is relevant both in patient empowerment in rehabilitation and empowerment in co-design.

4.2 Participatory Design

Participatory Design (PD) is a principle-based design field with power issues at the core of the agenda. In Chapter 3, I presented what PD as a design field entails, the principles on which it is based, and how participation stands at the core of PD. Drawn in previous literature, I concluded that empowerment outcomes in co-design entail participants that "have a say" in the design process, influence the decision-making and influence the design outcomes. This chapter presents some concepts and theories that I found useful in analyzing empowering practices in co-design with MACI people.

4.2.1 Design Ideas and Design Decisions

In the previous chapter, building on previous studies of the design process and PD principles, I concluded that having a say, influencing design decisions and design outcomes are empowerment outcomes in co-design. Understanding the design process on how ideas are generated and what decisions are made helps me study empowering practices for MACI people that will enable such outcomes for them in co-design.

Bratteteig et al. (2016, p. 16) say that "designing is a process, in which problems are set, and solutions are found and evaluated". Problems in design are usually wicked problems and are ill-structured. Thus, designers or participants in design will learn more about the problem itself while exploring solutions. Bratteteig and Wagner (2016a, p. 10) state that:

> "...design is about widening the range of choices before taking a decision on which of the choices to concretize in a design move. This is a process that opens up new choices, while closing others – both the opening up and the closing of choices are essential in design (see also (Bratteteig and Stolterman, 1997))."

The authors' understanding builds on Schön (1983) study of a designer's work where design work is seen as compounded of sequences of "seeing-moving-seeing". Schon argues that a design move consists of seeing the current situation, make a move to change it, and evaluate it afterward to see how that move has contributed to advancing toward the final result. Hence, based on Schön (1983) a design idea is what the move is about. In every sequence, the design advances toward a more concrete outcome. That is why design moves involve different kinds of seeing (Schön and Wiggins, 1992): seeing what is there in visual form, seeing with a set of appreciation system (as an act of judgment) that influences your seeing, and seeing as detecting the consequence of a move. They (ibid) also highlight that due to limit awareness or limited capacity to process complexity is not possible to take into consideration all the domains applied for seeing from the first move. That is why the process is described as sequential. They also discuss about the move experiments as different ideas that the designer tries out before affirming a move (Schön and Wiggins, 1992).

Moreover, Bratteteig and Wagner (2016a, p. 10) build on Alfred Schutz's notion of choices based on which a design is about creating alternatives to chose from. Choices, they say, citing Schutz, are based on a combination of projecting in the sense of anticipating 'future conduct by way of phantasying'. So, design ideas are possible choices. Choices can be regarding the vision of a project up to a more detailed and technical one in later sequences of the design. A design decision is related to the selection of one of the design choices. The decision or the choice made would open up new choices and so on.

Base on this understanding of the design process as a sequence of design moves Bratteteig and Wagner (2016a) have defined the road to design decisions through processes of:

- creating choices (or design ideas),
- selecting (deciding which of these ideas to take up)
- concretizing the idea in an evolving set of sketches and prototypes

- and seeing/evaluating the concrete result

In this thesis, this disentanglement of the design activities is very relevant in investigating empowering practices for co-design with MACI people. To make a power-weak group have a say in design, influence decision-making, and design outcomes, the designer or researcher should facilitate and motivate them to generate design ideas as choices, select them, concertize them in sketches and prototypes and evaluate the design are empowering practices that should be investigated.

Bratteteig et al. (2016) present a study of the journey of a design idea to a design decision in a cooperative design project. This is different from Schön (1983) study where the focus is the individual designer in the role of the reflective practitioner engaged in a process of reflection-in-action with the material at hand. Usually, in PD projects, many stakeholders may be involved and design ideas go into an evaluation within the group, involving a collective reflection-in-action. In this situation, the decision-making is not based anymore only on the designer's reflective process, but decision-making is influenced by the dynamics in the group. Shared experimentation and reflections are an essential part of a co-design session in PD projects.

Bratteteig et al. (2016) defined individual ideas as statements. They have found that statements that are supported by a significant number of design participants move to become design ideas - possible choices. This also happens with those ideas that are represented visually in the situation. Instead, if a statement is not supported in the group, it is intended to die. Moreover, they found that to promote design ideas, stakeholders belonging to the same group create alliances for and against design ideas. Different powers are enabled and surface in the workshop. In some cases, 'power to' (ability to design) sketch and visualize ideas is used to create 'power over' or domination on the others' ideas (ibid).

The case that Bratteteig et al. (2016) have analyzed describes a workshop where stakeholders have different power/knowledge that they use in favor of their ideas. However, they do not belong to some socially constructed hierarchy of power, like in the patient-healthcare practitioner relationship.

In the dichotomy patient–healthcare practitioners, the later prevail on the patient in a social structural context. Healthcare practitioners have been trained to give care, and the patient has inherently a trust in their knowledge. Even though the construct patient-doctor does not mean that the doctors have power over the patient in the sense of dominance, still a paternalistic relationship exists. This also emerges in PD projects where patients and healthcare practitioners should be involved in designing digital solutions that would be commonly used among the two. Thus, PD researchers in these cases have the task of orchestrating a meaningful dialog with and among participants from the start in order to ensure value conflicts are transcended and translated into meaningful design concepts.

Reflecting on the literature presented above, when co-designing with MACI people, there are two different situations to be taken into consideration: First, is the MACI person in co-design with the designer as a facilitator - What practices and artifacts can aid an MACI person in a co-design session to have a say and generate design ideas? What elements should be considered to prepare the space for design?

Second is the involvement of the MACI people in co-design together with healthcare practitioners and the designer/researcher (as facilitator) - How to aid them to have the possibility to generate the design ideas (so have a say), make it possible that they contribute to decision-making, and have their design ideas implemented in the design outcome?

Practices that contribute to the first part create the ground for the second part as well.

4.2.2 Balancing Power

A relevant principle in PD is the balance of power in decision-making among the different stakeholders involved in the PD process. Power imbalances discussion and the aim for the empowerment of marginalized user groups have been in the core of PD since the start and have expanded even more by involving new user groups.

Problems of power have remained a recurrent theme in the PD literature, and Bratteteig and Wagner (2014) in their book "Disentangling power in PD" have analyzed power as a concept, discussed the different kinds of power that surface in PD projects. Power relations in PD have been analyzed and discussed in relation to the influence in the decision-making on what can be part of the design result.

Bratteteig and Wagner (2016a) have noticed in PD projects both ′power over′ and ′power to′ as referring to two different phenomena. They have discussed these two concepts as two aspects of a single concept of power, which occur together in a PD project. Bratteteig and Wagner (2016a) comply with identifying power in PD as the ability to contribute (power to) but at some time keeping in mind the relational aspect of any kind of power (power over). PD is about having the possibility to contribute and share power with other users involved in the design process. Hence both aspects need to be examined. Bratteteig and Wagner (2014) also refer to another concept of power in PD - ′power with′, signifying the power of the people united, moving to achieve common ends. This is in analogy with the positive-sum power (Haugaard, 2012) and contributes to a discussion of power as something that should be kept in balance throughout the PD projects.

Relational concepts to power are influence, trust, and loyalty. While power represents an intervention in others′ action spaces, influence has to begin with one′s interaction partners′ own disposition to act, how they develop opinions and make decisions and not – as in the case of "power with" pushing through what already has been decided. Trust emerges in those situations where the benign intention is expected. Instead, loyalty is the feeling that trust between others can be maintained in the long run and therefore restored in the future if absent at any given time. The concept of empowerment is as well involved in the power discourse in PD. Bratteteig and Wagner (2014) state that the discourse about participation traces the notion of empowerment back to the pedagogical work of Paolo Freire, who believed that community empowerment starts when people listen to each other, engage in dialog, identify their commonalities and develop solutions for their own problems.

Micro-Power Relations

While analyzing power relations at the level of the PD projects is very relevant for defining the course of the project, there is also the power game that is played among the actors in-situ when different stakeholders come together in designing digital solutions that concern them all in PD session, being this a workshop or focus group. To distinguish from the decision-making on the project level, I have used in Paper V "micro-power relations", to refer to the power relations surfacing during a PD session among different stakeholders inspired by the term micro-mobility by Luff and Heath (1998). Thus, for PD researchers in the workshops or focus groups falls the requirement to balance the micro-power relations as part of the PD principle of achieving a democratic practice where all are represented in the final design equally.

Power imbalances have been discussed by looking at the decision-making process, and who of the actors involved has influenced the decision making, which has shaped the final design result (Bratteteig and Wagner, 2014). Thus, in order to have a balanced outcome, all the stakeholders involved in PD should contribute to the final design result.

The understanding of power and how it has been discussed in PD literature is relevant when it comes to the discussion of the empowering practices and the influence they have in making possible the balance of power in co-design with MACI people.

4.3 CSCW and PD

CSCW and PD are both fields of interest for this thesis and those fields where I contribute. In CSCW, I contribute by presenting a complex cooperative setting like rehabilitation and applying and discussing CSCW concepts in this setting. In PD, I contribute through knowledge of conducting PD with a user group that has not been in PD researchers' attention, the MACI people. In this section, I introduce how CSCW and PD and their relation have been discussed in the literature, and then argue how the two are interrelated in this thesis.

Greenbaum and Kensing (2012, p. 23) while describing the heritage of PD, state that "a group of CSCW researchers that were more interested in issues of power and democracy in the design process created the PD conference in 1991". Indeed, both fields initiated almost in the same period, and some researchers have been contributing to both. The two fields have their differences and also cross points in some specific research cases, such as the study presented in this thesis.

A comprehensive account of how the two fields interrelate with one another is the paper by Kensing and Blomberg (1998). PD is concerned with user participation in democratic practices in design by using different tools and techniques to make this possible. PD approaches and methods and techniques, can be relevant in designing information technologies for cooperative work. However, they are not the only focus of PD, which recently has expanded in different domains and the design of solutions for a wide range of reasons. Instead, CSCW is concerned with the design of information technologies that support cooperative work. The CSCW's commitment is to understand the sociology of work for developing better technologies and contributing to the way people work together. However, CSCW does not commit to giving workers a voice and a democratic process of design (Grudin, 1991). Thus, it can integrate different design approaches.

However, this does not mean that they do not relate to each other. Kyng (1991) discusses design for cooperation and cooperation in design. PD can learn from the understanding of cooperative work from CSCW in order to enhance cooperation and involvement during design sessions. Instead, CSCW can benefit from PD practices in designing CSCW solutions that are more welcomed in the workplace (Bannon, 1993). Moreover, discussing the power issues in the cooperative space can help in building strategies to facilitate cooperation. The PD approach provides several useful propositions relevant to the field of CSCW. For example, techniques for analyzing cooperative work and a deeper and more coherent understanding of the magnitude of aspects of a work situation which might influence the cooperation.

So, CSCW and PD are two scientific fields with different main aims. One is focused on cooperative work and designing computer support for it. Instead, the other is interested in the issues of users' participation in the design process of new technologies, closely related to the discourse of democratic practices and power balances in design. However, there are some cases where the two disciplines meet. While both fields have consolidated themselves, there are quite often researchers whose research is positioned where the two disciplines meet.

Such a case is the one in which the cooperative work should be renegotiated due to a group's requirement for empowerment in the cooperative space. To negotiate the cooperative practices and cooperative artifacts, a democratic process of design can contribute to a result where all cooperating actors can be satisfied. This is the case of patient empowerment in rehabilitation. The patients should be empowered in the cooperation. Thus, cooperative practices should support the empowerment of the marginalized user group that are the patients. The empowerment starts by empowering this user group in the design of the cooperative practices and artifacts. Empowering MACI patients in co-design would contribute to empowering results in rehabilitation.

In this thesis, in CSCW is in focus a situation of cooperative work where there is a power imbalance between parts cooperating that influences cooperation. Thus, cooperative practices that promote the balancing of powers are investigated. Instead, in PD is in focus the co-design with a group that has cognitive challenges and need support in co-design. However, the co-design case is the one of a CSCW system where the two stakeholders involved have imbalances in power which should be addressed in the co-design process as well.

CHAPTER 5

RESEARCH APPROACH

> "A method is more important than
> a discovery since the right method
> will lead to new and even more
> important discoveries."
>
> *L*ev Landau

Scientific research is strongly influence by the research approach we apply. Hence, I present and discuss in this chapter the paradigms, approaches, and the research activities for answering to the research questions introduced in the first chapter.

The chapter starts by reflecting on my worldview in relation to different classifications of paradigms presented in the literature. I then discuss the approaches I have used to answers to the research questions. I have used a Participatory Design (PD) and Ethnographic approach to investigate the empowering practices and design of empowering artifacts for patient empowerment in rehabilitation. In investigating empowering practices for people with Mild Acquired Cognitive Impairments (MACI) in co-design, I have integrated theoretically inspired PD workshops and reflection of such workshops.

Further, under research implementation, I report four parts of the research that I refer to as "research blocks". In each block, I present a rich picture of all the research activities that I conducted. This is followed by a presentation of the analysis methods for the data collected. I then argue the ethical considerations and conclude the chapter by reflecting on my role as a researcher and designer during the study.

Writing this chapter has been both challenging and developmental for me. I was involved in a self-reflection process in defining the theoretical borders I belong in terms of paradigms, methodologies, and analysis modes. I found myself and my study in many cases as in-between. Somehow, I felt the same confusion and IN and OUT pressure that my MACI participants felt. However, I chose to see these boxes as not a delimiter of me and the work that I have done in my study, but as an opportunity to reflect and present where my research meets with one category or another.

5.1 Positioning

I this chapter I discuss my positioning in the scientific inquiry and how I answer the ontological, epistemological, and methodological questions regarding, respectively, the form and nature of reality, the relationship between the ″knower″ and what can be known, and how the researcher can go about to find out (Guba et al., 1994).

Thomas S. Kuhn introduced the notion paradigm in his book stating: “these I take to be universally recognized scientific achievements that for a time provide model problems and solutions to a community of practitioners” (Khun, 1970, p. viii). A paradigm is a basic belief system built on ontological, epistemological, and methodological assumptions (Guba et al., 1994). It represents the worldview of the beholder. I will initially present the lenses on which I see the world based on my background and then present different classification of paradigms and discuss were my worldview fit within them.

My worldview

I was born in Albanian in 1991, only a few months apart from the big student movement that brought the end of the dictatorial regime[1]. The environment in that period was chaotic. People who were freed from a regime of dictated choices were now faced with a pluralism of choices that they did not have knowledge and practice on how to handle. What had happened would not easily be forgotten. The generation of peoples that were mature when the regime changed had still deeply rooted in their minds what a dictatorial regime meant. One concept that I talk a lot about in my thesis, "the cooperative work," was immediately in people’s memory associated with the forced voluntary work during the communist years and also the collectivization of lands and livestock. People were afraid of the power structures but at the same time did not know how to live differently. Thus, they established new ways of power structures that lead to more corrupted systems under the umbrella of a democratic regime.

Despite this situation I was born on, I could not relate to the anger of the past. My generation is the first generation freed from communism memories. Moreover, through the help of media initially in the form of TV channels and also through the more massive use of the internet and further mobile-phones, we learned more about forms of organization and values of well-functioning societies. We also grew in a transitional Albania where what we learned in

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[1] Student Movements 90-91 Rama (2019)

theory about more developed countries and what we saw implemented in our daily life were incompatible. Hence, we built the will, the courage, and the knowledge for change.

I saw during the transition years of Albania how a society can change radically in a short period. How the reality that we, as researchers study, changes based on the historical context in which we are in and in this way influences our studies. Moreover, the chaotic situation of transition made me also aware and believe that it is through transactions with others that we can change the world around us. Being aware of problems of the period made me use critical lenses of making sense of the reality. The critical perspective toward reality is targets those situated practices that do not add value to people's lives and need change. Hence, that is where my interest in empowerment and empowering practices stems. Moreover, I think that we can find out knowledge by engaging in the constructed realities with the people belonging in it. When studying empowerment this is even more relevant. Empowerment is critical and should emerge by people wanting to change their position in a specific situation in society. It is by considering their "say" where the practice for empowerment should emerge.

Positioning in paradigms classifications

Different classification of paradigms have been described in the literature (eg. (Guba et al., 1994; Duarte and Baranauskas, 2016; Myers and Avison, 2002)). Guba et al. (1994) have defined four paradigms: positivism, postpositivism, critical theory, and constructivism. Later, when discussing their initial classification in Lincoln et al. (2011), they also include the participatory paradigm (building on the work of Heron and Reason (1997)).

Guba et al. (1994) have argued that it is not always the case that researchers strictly sit in one paradigm, and the boundaries of paradigms are quite often porous. Indeed, I find it challenging to position my worldviews to a single paradigm described above. I argue that ontologically, a critical-constructivism paradigm is more compatible with my worldview. However, methodologically, I find the participatory paradigm more compatible.

The critical theory ontology relies on a historical realism crystallized over time as a set of specific values. Epistemologically, the researcher's relationship and what to be known is transactional and subjective, and findings are considered value-mediated. Instead, constructivism, on the other side, claims that findings are created and constructed together, and it pertains to a relativist ontological perspective, where the reality variate in relation to our interactions. In my background I presented how I see the reality as historically constructed and I consider knowledge as located in peoples' realities and only through engaging with them we can create knowledge. Hence, I adhere to both critical and constructivist paradigm.

Instead, methodologically Lincoln et al. (2011, p. 168) lists in the participatory paradigm these: "a political participation in collaborative action inquiry; primacy of the practical; use of language grounded in shared experiential context”. These make me think of the participatory paradigm methodological perspective closer to the way I went about finding my knowledge with a subjective perspective where knowledge is co-constructed with the participants in the study.

Another classification of paradigms in information systems, and commonly used in Computer Supported Cooperative Work (CSCW), is presented by Myers and Avison (2002). The three paradigms are positivist, interpretive, and critical. Even in this classification, the authors argue that despite the philosophical difference between the paradigms, there is no clear-cut between them in the practice of social research.

In this classification of paradigms in IS research, I find myself belonging to the critical - interpretive paradigm (Howcroft and Trauth, 2005; Willcocks and Mingers, 2004). According to Myers and Avison (2002, p. 6), the interpretive paradigm sees the “access to reality through social constructions such as language, consciousness, and shared meaning”. Instead, the critical theory assumes that “the reality is historically constituted and that it is produced and reproduced by people”. Critical research focuses on the oppositions, conflicts, and contradictions in contemporary society and seeks to be emancipatory. I see the access to reality through the social constructions, but I see this reality as historically constructed and in need of change for the benefit of some groups that have been in a power weak position. Research on "empowerment" is inherently positioned within the critical paradigm. However, my aim is to find ways to operationalize empowerment, and this can be achieved on my worldview by discussing this with people influenced by the empowerment and investigate their meaning and interpretation of empowerment.

The critical - interpretive paradigm position is also supported by the research approaches that I have chosen - PD (critical and emancipatory) and ethnography (interpretive and descriptive) - and from my self-positionality as a thoughtful reflective designer as defined by Löwgren and Stolterman (2004). Taking a critical design approach for my research, I explore the relationship between the patients and healthcare practitioners in relation to patient empowerment in rehabilitation in a subjective way. However, I aim to critically explore patients’ and healthcare practitioner practices of cooperation and reflect with them for possible improvements that will lead to empowerment. So, my aim is not just to interpret reality based on local and subjective interpretation but also to critique it and try to improve the actual positions. I take the same approach in the investigation of empowerment of MACI people in co-design, where I apply PD methods theoretically inspired and then critically reflect and interpret how the MACI people interacted in the co-design and propose the findings as possible empowering practices and artifacts.

5.2 Methodologies

In the previous section, I presented my reflections on my worldview and the paradigms that resemble it. Paradigms are also influenced or influence how we go about conducting our research.

A qualitative approach has been used for conducting this research. Qualitative research is an umbrella term for an array of attitudes toward and strategies for conducting inquiries that are aimed as discerning how human beings understand, experience, interpret, and produce the social world (Mason, 1996). Based on this definition of qualitative research, my preference for naturally occurring phenomena, and the emphasis on meaning, I can state that a qualitative approach is an appropriate approach for conducting my research.

Myers and Avison (2002) discuss four types of methodologies: Case Studies, Action Research, Ethnography, and Grounded Theory. According to them (ibid, p. 7) case studies are the most common methodology within qualitative research. Stake (2005, p. 444) defines a case study as "both a process of inquiry about the case and the product of that inquiry" . Case studies can be classified as explanatory, exploratory, descriptive, multiple, intrinsic, instrumental, and collective (Baxter et al., 2008). An instrumental case-study facilitates the understanding of something else. The case is studied in depth because it helps the researchers to pursue an external interests.

In order to investigate empowering practices for patient empowerment in rehabilitation and how to design empowering artifacts that will support these practices, I have studied in-depth the case of cognitive rehabilitation at Sunnaas Rehabilitation hospital.

Additionally, for studying empowering practices for involving MACI people in co-design within the group and with other stakeholders that have power imbalances with the MACI people, I analyzed in depth the case of co-designing cooperative artifacts for MACI patients empowerment in the rehabilitation process.

Both parts of my research become instrumental case studies of one another. Patient empowerment in rehabilitation is studied in the case of cognitive rehabilitation of MACI people. Instead, empowering MACI people in co-design has been studied to design a cooperative artifact for the empowerment of the MACI patients in the rehabilitation process in cooperation with their healthcare practitioners.

However, the instrumental case studies have only provided a context for me to conduct my research and do not represent my methodology. I found it difficult to position my research activities in one of the methodologies that Myers and Avison (2002) list. In different parts of my research, I have different methodologies prevailing, and their combination has contributed to have a broader range of data and study the phenomenon of my interest more in-depth.

I have chosen to take a PD and an Ethnographic approach for collecting data and better answering my research questions. Verne and Bratteteig (2018) in an analysis of suitable research methodologies for design researchers, position both PD and ethnography as relevant methodologies in those cases where 1) the user is considered as the owner of the research problem, 2) the user contributes in the perspective of research, and 3) the user contributes in the delineation of the research area of concern. PD and Ethnography are considered suitable for the critical paradigm and for constructive research questions such as in my case. While ethnography has been defined both as a method and methodology, PD researchers are more hesitants to define PD as a methodology and usually refer to it as a design approach. I will use the term approach for both PD and Ethnography in this thesis and accommodate them as the main "methodologies" (under which I apply different methods) for different parts of my research, which in combination with one another help me investigate answers to my research question. Ethnographic studies and PD research have a long tradition of being combined in research (Blomberg and Karasti, 2012; Mörtberg et al., 2010; Shidende et al., 2017).

In the following subsections, I present my arguments on why a PD approach is relevant in my study. Then, I introduce ethnography and ethnographic research and how it also is relevant to my study. Finally, I conclude with a discussion on how Ethnography has been positioned within PD.

5.2.1 Participatory Design

The reason why PD has an important role in this thesis has been presented since the introduction. Designing cooperative artifacts that aim at patient empowerment in rehabilitation also requires an empowered patient in such artifacts' design process. PD is that design approach concerned with power issues in the design process, making it suitable for designing cooperative artifacts for empowerment. So, PD is an inquiry approach for investigating empowering practices and design implications for patient empowerment in rehabilitation. While using PD to investigate patient empowerment in rehabilitation, I have also investigated the empowerment practices and artifacts for empowering MACI people in co-design. Hence, PD is not only an inquiry approach but also a field where I contribute back with knowledge.

Blomberg and Karasti (2012) present a summarized version of the principles of PD when discussing PD in relation to ethnography. They (ibid) highlight that in PD, there is a focus on respecting different knowledge and the unique experience that each brings in the design space. This should be coupled with mutual learning opportunities, where people can gather and negotiate knowledge and values. Another principle is the joint negotiation of project goals. People will be more motivated to participate in the design space when they recognize that their contribution is considered valuable. To make possible the mutual learning and negotiation of goals, tools and techniques carefully selected facilitate the design process.

A central part of patient empowerment is the cooperation between patients and healthcare practitioners. PD and the principle of collective reflection in action provide the setting for negotiating the cooperation by sitting together and discussing options. Moreover, PD has the commitment of making participants have a say and influence the outcome on issues of their concern. Patient–healthcare practitioners' relation is somehow influenced by paternalistic behavior that comes from a patient's position as "someone that suffers" and needs help. Hence, PD is committed to giving a voice to the patients to influence the cooperation that would contribute to their empowerment. Moreover, the PD principle of mutual learning contributes to patients and healthcare practitioners learning on each other's views on empowerment practices and create the environment for negotiation of these views.

Hence, a PD approach is suitable for studying empowering practices and design implications for designing artifacts for patient empowerment in rehabilitation. Regarding empowering practices and empowering artifacts for MACI people empowerment in the co-design process, I have applied a theoretically drawn experimental approach. This means that I have been using theoretical knowledge to plan PD workshops with MACI people, so the process would contribute to making MACI people have a say, influence decision-making, and influence the design outcome. Then, I have facilitated such workshops and afterward reflected on my first-hand experience or analyzed the workshops' recordings in relation to the empowerment outcomes.

Conducting PD workshops and reflecting on them is suitable because it gives me the possibility to experience the challenges or opportunities that MACI people can face in co-design.

5.2.2 Ethnography

Ethnography is a research approach that has traditionally been used to understand different cultures. It has developed from anthropology, and it aims to produce rich descriptions of specific settings. Rich research consists of a range of grounded and relevant facts, observations, understandings, perceptions, and interpretations (Tacchi et al., 2003).

Ethnography, as defined by Hammersley and Atkinson (1995, p. 1), is "...a particular method or set of methods. In its most characteristic form, it involves the ethnographer participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions.". Another good definition of ethnography is given by Brewer (2000, p. 6) stating that "Ethnography is the study of people in naturally occurring settings or 'field' by methods of data collection which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner." Through reflective observation of the current situation, ethnography helps in giving a rich understanding of the research community (Tacchi et al., 2003).

Blomberg et al. (1993) as stated in Blomberg and Karasti (2012) list four principles of ethnographic research such as a) studying phenomena in the everyday setting, 2) taking a holistic view on the study of a phenomenon, 3) providing a descriptive understanding, and 4) taking members' perspective.

So, ethnography is a methodology that aims an exploration of a phenomenon in its environment, as it happens, from the perspective of people that are part of the phenomenon, and, by trying to understand also the environmental factors that might influence such a phenomenon. Ethnography is concerned with descriptive accounts. However, this does not mean that ethnographic research has not or can not contribute to society's changes. Blomberg and Karasti (2012, p.88) referring to the early work of Suchman et al. (1999) state that they developed the saying, "Innovation is an imagination of what could be based in knowledge of what it is". Hence, ethnography can have a strong contribution to bringing change and innovation.

In ethnography, the researcher can have a double role such as "peripheral membership" when it comes to observing others' work and/or "active membership" as a change agent within the organization (Barab et al., 2004).

To investigate empowering practices and artifacts in rehabilitation creates a necessity to know how the rehabilitation practices are currently arranged and what are those things that are not working as they maybe should. Moreover, rehabilitation has in place practices that promote an engaged patient in the process. Analyzing the rehabilitation practices in relation to their influence on empowerment outcomes helped me in defining some empowerment practices that are currently in use in rehabilitation and should be taken into consideration by other healthcare settings.

Ethnographic studies have also contributed to designing practices and artifacts. The knowledge of the current situation can promote a discussion of what should change in the future. Thus, ethnography can contribute to envisioning future solutions during design activities. In the next subsection, I present how ethnography and PD have been used together in design.

5.2.3 Ethnography and Participatory Design Research

Ethnography and PD share common principles and can also contribute in strengthening the knowledge generated by each.

Ethnography's commitment to study people and phenomena in their natural occurring setting and the emphasis on the local setting as the primary setting of knowledge dovetails with PD principles of respect toward the values and knowledge of workers and designers. Both fields are interested in situated-based actions and working with people in their workplace or home. Designers and ethnographers have to search for knowledge in the settings where the phenomena of their interest are happening (Blomberg and Karasti, 2013).

Moreover, ethnography has a holistic notion and requires activities to be analyzed within a larger context. This is an important reminder for the designer in the PD projects that their work has to surpass the limits and constraints of the design space, and it should conceptualize the design artifact in the larger context in which it will be used (Blomberg and Karasti, 2013).

However, ethnography's commitment to describing the current situation is considered a downside when promoting and pushing forward innovation. The descriptive understanding of the current situation is interpreted as a noninterventionist approach of ethnography (Blomberg and Karasti, 2013). Instead, PD explores new designs and new alternatives. Nevertheless, above, I quoted that innovation has been considered as emerging on the situation "as-it-is". Hence, ethnography can contribute to exploring change.

Participation is relevant in both approaches, but the issues on participation differentiate. In PD, participation is discussed mostly in terms of user active involvement in the design process and efficiently bringing them into the design table. Instead, in ethnography, people live in their natural setting, and participation is discussed from the researcher's standpoint and how s/he will engage in the life of the studied community. In my study, I had to take the ethnographer and designer position. I reflect on such experience at the end of this chapter.

Despite the differences and similarities, ethnography and PD methods and techniques have been used together in PD and CSCW projects (Blomberg and Karasti, 2013; Simonsen and Kensing, 1998; Mörtberg et al., 2010). Blomberg and Karasti (2013) and Blomberg and Karasti (2012) have discussed some alternatives on how to position ethnography in PD. Among the options presented are:

"Ethnographically informed design as interdisciplinary research", including:

- Ethnography workplace studies unencumbered by design - there are studies concerned with understanding social phenomena via detailed descriptions of work practices and with exploring conceptual and theoretical issues in social science
- Ethnography as input to design - Ethnography is used to expose aspects of work setting and these knowledge is later used by designers. Ethnography is considered as a method that contributes to design altogether with other methods. This is called rapid ethnography or quick and dirt ethnography.

The other option is "Ethnography and PD as a multi-perspectival collaboration" - In such a case, the ethnographer can become a mediator for PD, s/he can be involved in mutual learning, or ethnography can be used to foreground user/participation.

Moreover, they have discussed a re-conceptualization of the relation between PD and ethnography, and they list Case-based prototypes, Co-realisation, and Design ethnographies as ways to integrate PD and Ethnography. Design ethnographies represent a new way of conceptualizing the relationship between PD and ethnography, where ethnographic techniques and ethnographically collected data are integrated within the design activities. Blomberg and Karasti (2012) refer to Blomberg et al. (1996, p. 240) to exemplify design ethnography as:

> "...involve[d] cycling among studies of work, codesign, and user experience with mock-ups and prototypes of new technologies...

> [where] work practice studies [are] embedded in design activities, whereas design efforts contribute to work analysis.”

It is this Design Ethnographies, cycling from design to ethnography, that I take in some parts of my study to design and analyze the new practices for empowerment.

In conclusion, I have applied PD and Ethnography, and I have combined them in different ways, either as Ethnography workplace studies unencumbered to design, Ethnography as input to design, or Design ethnographies when it comes to exploring patient empowerment in rehabilitation. I present in the next subsection my research implementation divided in research blocks. I return to the different types of PD and ethnography relations when I present my research blocks.

5.3 Research implementation

In this section, I elaborate on the practical ways (tactics) in which the research was operationalized to support findings.

The majority of research was conducted at Sunnaas Rehabilitation Hospital premises, and some activities were conducted in the rehabilitation center of a municipality in Norway. In the following subsections, I present in detail four research blocks and the methods used for data collection in each of them. Then I introduce the methods used for data analysis.

Before starting with each of the research blocks, I want to describe the activities that happened beforehand. When I was granted my PhD position, Sunnaas and Østfold University College (HiØ) had already built a first common ground of problems that the hospital wanted to solve and possible research approaches that HiØ wanted to explore while contributing to Sunnaas’s interest. My two supervisors, Harald Holone and Frank Becker were the ideators. When I joined the team, I started working on my research proposal.

Among the first activities was to get myself involved with the literature on rehabilitation, technologies in rehabilitation, and the designing process of these technologies. It had been previously discussed that I could conduct my research at the Cognitive Rehabilitation Department (CRD) as one of the departments at the hospital that was accustomed to researchers’ presence, and that could represent an interesting case of study for the organization of work in rehabilitation. Moreover, the patients who receive services at the CRD belong to a user group that I, as a PD researcher, was interested in.

In the first weeks of my PhD, I had a meeting with my two supervisors from Sunnaas and HiØ, the Head of the CRD and an IT expert at the hospital. They presented me with the hospital and their needs, and I also presented some knowledge gained from my literature review regarding interesting research approaches that could be relevant knowledge for them. While I wrote my research proposal, I was in continuous discussion and collaboration with my supervisor at Sunnaas and the Head of the CRD. This thesis has no major change in comparison to the research proposal submitted.

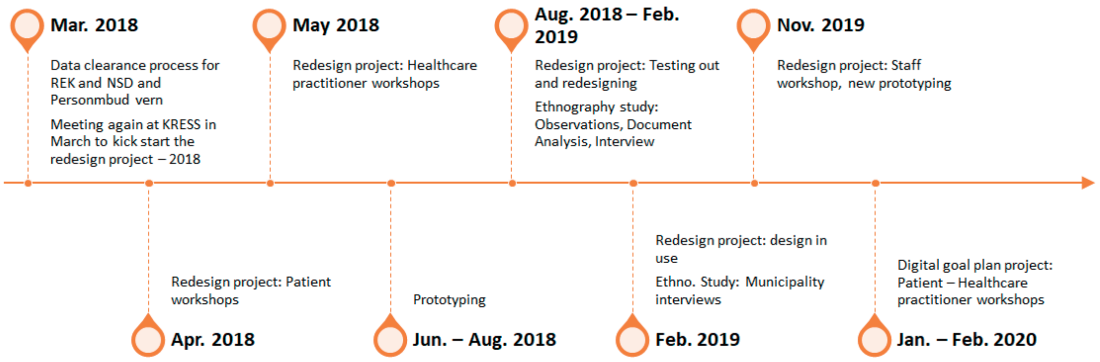


Figure 5.1: Projects timeline

Furthermore, we continued the application for collecting data. My Sunnaas supervisor facilitated that process, and I was granted a laptop from the hospital that I could use to access and store data collected throughout my research. Once everything was cleared, I was finally granted access to the hospital for starting my PhD journey. In between this period, it has been extensive coordination through emails and two more additional physical meetings. The actions on how to best implement the research plan were discussed. The meetings were mostly mutual learning venues where I would present Sunnaas representatives with my research fields and research interest, and we would discuss how to shape the research questions together.

After this, a set of activities followed, which are related to four main research project blocks, which I present in detail in the next subsections. Figure 5.1 shows the timeline of how activities unfolded. I have included the name of the project and the specific activity within it. It is visible in the figure that the redesign project was going on while the ethnography study started. Instead, the ethnography study finished before the digital goal plan project and contributed to ideating and planning the digital goal plan project.

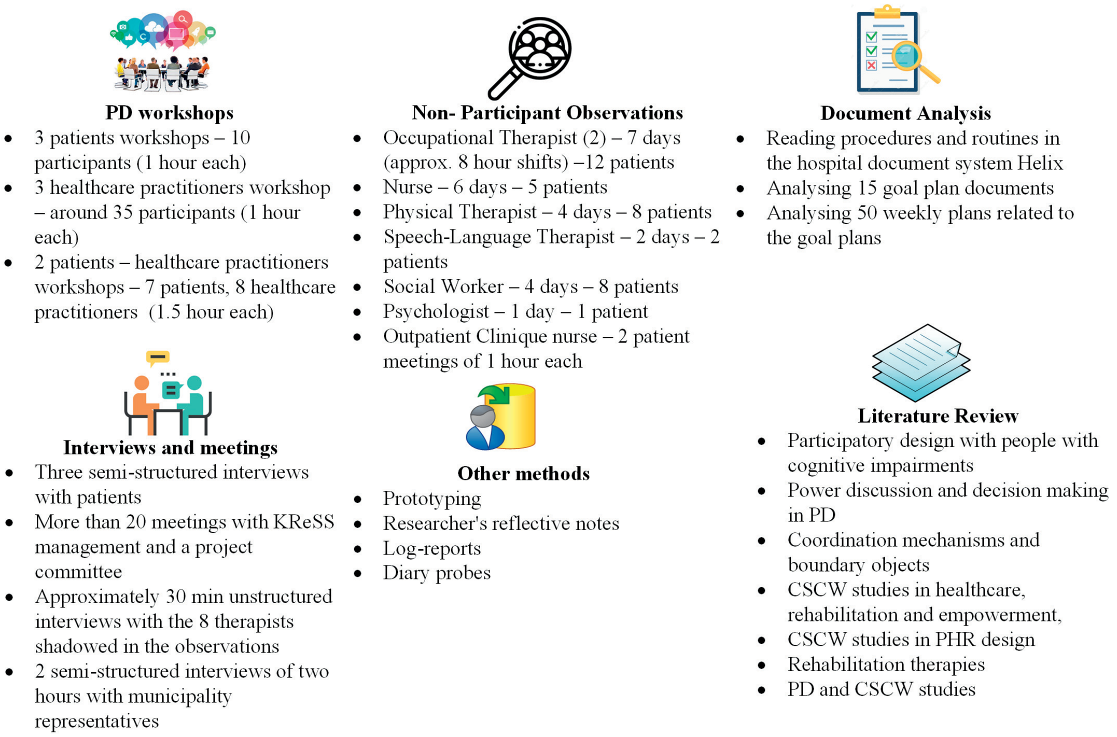
In my research, there are four parts of interest: MACI patients, CRD staff, CRD management, and me. Initially, I was in contact with the CRD management only. The request for researching how to design empowering artifacts and practices for patient empowerment in rehabilitation came from them. At least that was my first impression. Later in my study, when I was more involved in the department, I found that the management request was only a representation of what the staff also wanted and what the staff as patient proxies saw as necessary for patients' benefit.

Instead, the focus on empowering MACI people in co-design came from my interest in conducting a design study and promoting interested users' genuine participation in design. I was interested in co-designing with people with cognitive impairments, but I was initially not specifically acquainted with

MACI people. It was brought to my attention by the CRD manager when he described the condition as the "silent epidemic". I investigated PD literature for this user group, and the research was limited.

Moreover, with a PD mindset, the design of cooperative artifacts should involve in design all parts that will use the artifact. Hence, patients and healthcare practitioners would be involved in co-design together. The inspiration in focusing on balancing powers in such co-design sessions was from the start, considering patient-healthcare practitioners' paternalistic relations. However, this was confirmed once I started research at the CRD.

In Figure 5.2, I present a summary of the whole data collection process, distributed per method of data collection. This represents the whole set of my data that has been later analyzed with different research questions in the papers and for the two questions in this thesis.



PD workshops
- 3 patients workshops – 10 participants (1 hour each)
- 3 healthcare practitioners workshop – around 35 participants (1 hour each)
- 2 patients – healthcare practitioners workshops – 7 patients, 8 healthcare practitioners (1.5 hour each)

Non- Participant Observations
- Occupational Therapist (2) – 7 days (approx. 8 hour shifts) –12 patients
- Nurse – 6 days – 5 patients
- Physical Therapist – 4 days – 8 patients
- Speech-Language Therapist – 2 days – 2 patients
- Social Worker – 4 days – 8 patients
- Psychologist – 1 day – 1 patient
- Outpatient Clinique nurse – 2 patient meetings of 1 hour each

Document Analysis
- Reading procedures and routines in the hospital document system Helix
- Analysing 15 goal plan documents
- Analysing 50 weekly plans related to the goal plans

Interviews and meetings
- Three semi-structured interviews with patients
- More than 20 meetings with KReSS management and a project committee
- Approximately 30 min unstructured interviews with the 8 therapists shadowed in the observations
- 2 semi-structured interviews of two hours with municipality representatives

Other methods
- Prototyping
- Researcher's reflective notes
- Log-reports
- Diary probes

Literature Review
- Participatory design with people with cognitive impairments
- Power discussion and decision making in PD
- Coordination mechanisms and boundary objects
- CSCW studies in healthcare, rehabilitation and empowerment,
- CSCW studies in PHR design
- Rehabilitation therapies
- PD and CSCW studies

Figure 5.2: Summary of data collection methods

5.3.1 Research Block 1: Redesigning the goal plan document

I had planned two phases to conduct my study as presented in Research Block 2 and Research Block 3. The aim was to initially get to know the rehabilitation process at the CRD through observations in the department and then use these knowledge to involve patients and healthcare practitioners in co-design workshops. The workshops' focus would be to co-design cooperative artifacts that would support the cooperation between the patients and the healthcare practitioners to achieve patient empowerment. The design activities would contribute to answering the two research questions and sub-questions of this thesis. However, my plan slightly changed by adding an extra research block to my plan that gave me the opportunity to collect more data.

From the start, I found that at Sunnaas, there are currently in use cooperative artifacts shared between a patient and her/his healthcare practitioners. These were the goal plan document and the weekly plans.

As described in depth in Chapter 2, the goal plan document is saved in the hospital's Electronic Medical Record (EMR) system as a journal page with a specific format and where all the multidisciplinary team members related to a specific patient could make changes. This document is then printed and given to patients. The goal plan document is a document used by both patients and their multidisciplinary team. It represents information and knowledge on rehabilitation and a structured way of coordination of rehabilitation activities. Instead, weekly plans are weekly patient calendars for activities that the patient should do at the hospital during the week.

Before starting my observations, the CRD leader introduced me to their new initiative in redesigning the layout of the goal plan document so it could be more useful for the patients - make them more involved, understand and in control of their rehabilitation process and enhance their interactions with the healthcare practitioners. This was very much in line with my research, so they wanted me to be involved. I accepted to be part of the project by considering this project as a pilot project. This allowed me to investigate the needs for patient empowerment in rehabilitation directly from the viewpoint of patients and healthcare practitioners and to conduct PD activities with MACI people from the start.

The CRD leader created a working group for the project compounded by a team of healthcare practitioners and me. I proposed to have PD workshops with patients and then with healthcare practitioners to discuss their needs to redesign the goal plan. The aim of the design result was a new version of the goal plan. The research aim was to find out empowering practices and how to design the artifact to support patient empowerment in rehabilitation. Moreover, exploring ways to make MACI patients have a say in the co-design, influence decision-making and the design outcome.

I refer to this project hereafter as the "redesign project". I used the following data collection methods:

5.3.1.1 Future Workshops

“Future workshop” is a method presented by Jungk and Müllert (1987) to be used to engage citizens in decision-making processes in their communities. It was later integrated into PD by Kensing and Halskov (1991). Future workshop tends to start with a general discussion of a topic and critics about it and then after the critics coming up with ideas for improving the current situation. It gives participants the opportunity to think critically about the topic of concern and derive visions and future solutions for the problem(s). As Löwgren and Stolterman (2004, p. 70) state:

> "the aim of a future workshop is for future users or stakeholders to clarify the common problems in the current situation , create vision about the future and discuss how these visions could be realized."

According to Jungk and Müllert (1987), future workshops are performed in 5 phases: Preparation; Critique phase; Fantasy phase; Realization phase; and Follow Up. van der Velden and Mörtberg (2015) argue that future workshops for technology design produce action plans as outcome, which forms the first step in the materialization of requirements. I have applied a customized version of future workshops both with MACI patients and also with healthcare practitioners. I describe them in more detail below.

When discussing such a cooperative artifact as the goal plan, a PD approach requires all stakeholders that will use the artifact to be involved in the design. Instead of involving both patients and healthcare practitioners in co-design together, I chose to do so separately because I wanted to explore the need and view of empowerment by each group initially and then get involved in a negotiation design process between them.

Patients' workshops

Three patient future workshops (Jungk and Müllert, 1987) with respectively 4, 4, and 2 MACI patients participants, were organized in May 2018 - a detailed account of the patients' workshops is described in Paper IV. The workshops layout was initially planned to have two phases.

First, discuss the goal plan's role in their rehabilitation process and how it influenced patients' participation, understanding, and control of the rehabilitation process. Moreover, how the goal plan was contributing to the cooperation with the healthcare practitioners. Second, the patients were required to design a new version of the goal plan that would make them participate, understand, and in control of the rehabilitation process.

This layout was used only in the first workshop. I experienced in that workshop that the participants were hesitant to design a new version of the goal plan on a blank page. Thus, in the second and third workshops, the layout was changed. Three activities, more task-oriented, were involved.

First, participants had to look at the old goal plan and reflect for each of the parts in the document how relevant that information was to help them participate, understand, and in control of their rehabilitation.

Second, they had to look at those fields of the goal plan that they had judged as relevant and try to rewrite or redesign them in a way that would motivate them to participate, understand, and in control of their goal plan and consequently of their rehabilitation process.

Third, continue the redesign by adding maybe things that the patient thought would be relevant but was missing in the current goal plan. They could work on the old layout or take a blank page and design from the start. All 6 participants in the two workshops the layout was used designed their own goal plan.

In the preparation of the patients' workshops, I worked in close collaboration with the project committee in learning regarding patients' abilities and adapting the workshops' organization to such abilities. In order to enable mutual learning with the project committee, I conducted a future workshop with them that I had planned for the patients. This contributed to get the committee to provide concrete suggestions on how to improve such a workshop's layout. Suggestions were regarding duration, type of activities, how to enable patients' creativity and engage them in have a say and contribute to the design process. Some of these knowledge I had already reviewed in the literature. However, the first-hand knowledge that "domain experts" in the committee had, due to their many years of experience with the patients, resulted very helpful. The main contact point for me was an Occupational Therapist (OT). OT's role in supporting design processes in rehabilitation is recognized in the literature. Their professional knowledge of techniques that can facilitate patients' daily lives is very useful when engaged in creative research activities with patients.

The data collected from these workshops were audio recordings and workshop materials such as new designs of the goal plan document layout.

I had the role of the main facilitator during the workshops. A second facilitator from the hospital also assisted me. This was a person who had professional training in rehabilitation but did not directly connect with the patients while they were at the hospital.

In Paper IV, I define this person as "the knowledgeable third party". After each of the workshops, we reflected on our own perception of the workshops, what had worked and what not, so we could improve that in the next workshop. I noted the shared reflections down in my reflections diary. I did the same with my recall of reflections-in-action that I did while we were facilitating the workshops.

As it is understandable from the workshops' description, I conducted a changed version of the future workshops method. Some of the changes were: Instead of the critique phase, I used positive rhetoric by asking about possible improvements of the current situation. The reason was to not put patients in a negative mindset that could influence them negatively. I introduced a second step between the "critique phase" and the "fantasy phase", which I have called "the teaser of the future envisioning". This task is based on the current situation (such as the old version of the goal plan) and asks for concrete improvements of it. It serves to make the patients enter in the process of thinking about the future but still talking about things they know well.

Moreover, I did not continue into the realization phase and follow-up as the aim in these workshops was more exploring needs and ideas. Another reason was that healthcare practitioners suggested that a 1.5 hours long workshop was suitable to not risk tiring the MACI patients. Figure 5.3 shows examples from the patients designs.

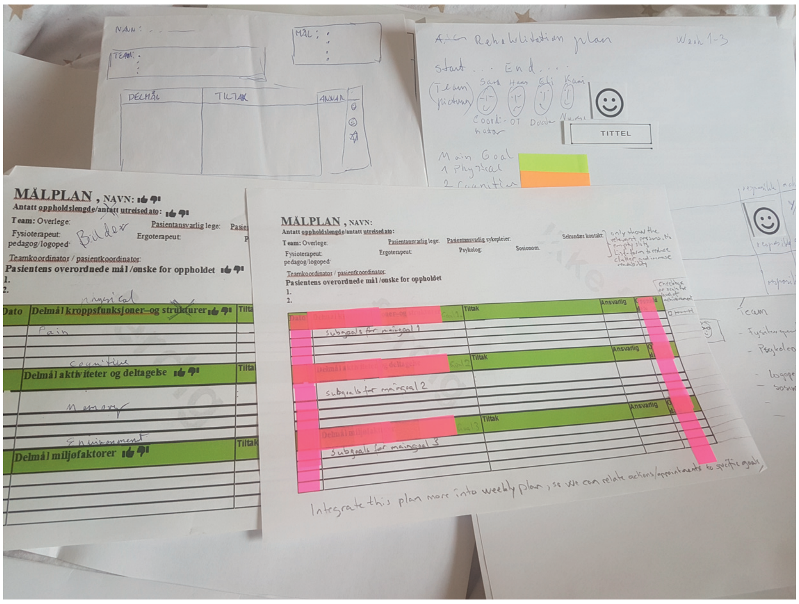


Figure 5.3: Suggestion of goal plan designs from patients in the workshop

Healthcare Practitioners' workshops

Two healthcare practitioners' future workshops were organized in June 2018 with, respectively, 8 and 8 participants. Each workshop lasted 1 hour and ran in parallel.

After the patients' workshops, I analyzed the recordings and the workshop materials for the 10 patients. In the analysis, I was assisted by the OT from the CRD that had helped me in planning the workshops. The findings were a list of requirements for changes in practices and the design of the goal plan layout. I then created a PowerPoint presentation for the project committee. Together with the project committee, we refined the codes from the analysis and landed on a final list of themes/requirements.

The project committee, together with me, decided that we want to use the list as a set of mandatory requirements to have in the new redesigned goal plan when starting the workshops with healthcare practitioners. Such a decision aimed to make the healthcare practitioners reflect on the patient needs and how these needs could be accommodated in the rehabilitation process.

The healthcare practitioners' workshops were divided into three parts: a presentation of the findings from the patients' workshops, then presenting the healthcare practitioners for a few minutes with a "mood board" (Garner and McDonagh-Philp, 2001) with possible designs of goal plans found on the net, as a way to enhance their creativity. Then the healthcare practitioners were asked to individually reflect on the patients' requirements and sketch suggestions for a new layout of the goal plan that would be suitable for them and fulfilled **all** the patients' requirements. We gave them both printouts of the old goal plan and white papers for designing the new one. After they had finished their redesign individually, we had a final session discussing the

Figure 5.4: Moments from the staff workshops

designs in the group and co-designing a new goal plan document as a group. At the end of the workshops, all the staff gathered in the main meeting room, and they shared the two designs from each group with each other and had one representative explaining the design to the other group.

I facilitated one workshop and the OT that had collaborated with me during the project facilitated the other workshop. The workshops were both set to be recorded. One of the recorders did not work properly, so we had to rely on one recording and two workshop materials with individual designs of the new goal plan from each of the participants. Figure 5.4 shows moments from one of the workshops.

All were given a workshop description and consent form a few days ahead and were collected before the workshop. The recruitment process was by the head of the CRD. The workshop was organized in one of those hours that was supposed to be group work and would not interfere with the work of many in the department. The project committee formed with healthcare practitioners of different disciplines, and my participation in some of the CRD staff meetings talking about the project's aim helped the recruitment. Many in the staff considered a similar activity a possibility to improve their work processes and services for the patients. Figure 5.4 shows moments from one of the workshops.

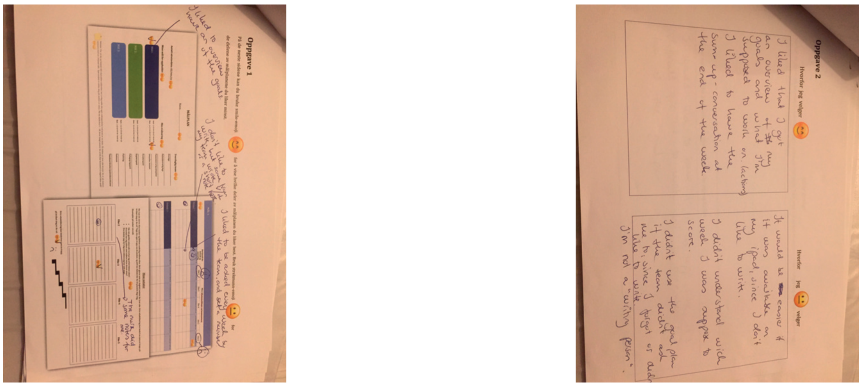
5.3.1.2 Prototyping and Testing

Together with the OT, we analyzed the healthcare practitioners' design suggestions from the two groups. The patients' workshops had provided us with the needs that patients had to be empowered in their rehabilitation process. The healthcare practitioners' workshops had provided me with suggestions for design that were also suitable for the healthcare practitioners and their cooperation with the patients.

Building on this knowledge, I created a Microsoft (MS) Word file prototype for the new goal plan. It went through many iterations of analysis and discussions with the project committee before moving further into testing. The aim was to test the MS Word prototype and then use the prototype to develop the new layout of the goal plan in the hospital's EMR.

The new goal plan document in MS Word format was set out for testing "in the wild" at the CRD from August 2018. This was accompanied by the creation of new procedures on how to use the new document. A way to work around without compromising the confidentiality, integrity, and availability of the information was found. The CRD representatives drafted the internal procedures, and the new goal plan was being used for every patient coming into the department. While healthcare practitioners and patients were using the new layout, continuous feedback on the prototype was provided.

Diary probes for evaluation for patients - In order to evaluate the prototype and gather the patients' opinion for the prototype, I created a diary probe (inspired by Gaver et al. (1999)), where I asked the patients for their opinion regarding different parts of the new goal plan: If they could easily understand each part of the document? If they liked it?, If they used the document at all? and What could be improved in the layout? The diary was given to five people. Two of them wrote their answers in the diary. One of them had not filled in information but accepted to be part of an informal interview where I asked questions about her opinion on the goal plan. The last two were two patients that participated in the workshops for redesigning the goal plan. I had an interview with one of them, and the other is the case of Olav, whose story I described in Chapter 2. Figure 5.5 shows two pages of the diary filled from one of the patients.



Oppgave 1

På de neste sidene kan du bruke smile-emoji 😊 for å vise hvilke deler av målplanen du liker best. Bruk strekmunn-emoji 😐 for de delene av målplanene du liker minst.

I liked to have an overview of the goals.

I don't like to write, but some from my team wrote a short note here.

I liked to be asked every week by the team, and set a number

The nurse did some notes for me.

Oppgave 2

Hvorfor jeg velger 😊

I liked that I got an overview of ~~the~~ my goals and what I'm supposed to work on. (actions)
I liked to have the sum-up-conversation at the end of the week.

Hvorfor jeg 😐 velger

It would be ~~[illegible]~~ easier if it was available on my ipad, since I don't like to write.

I didn't understand wich week I was suppose to score.

I didn't use the goal plan if the team didn't ask me to, since I forgot or didn't like to write.
I'm not a "writing person".

(a) Diary page 1

(b) Diary page 2

Figure 5.5: Evaluation diary for the new goal plan document

Evaluation notes by the staff - Meanwhile, on the healthcare practitioners' part, the OT was in charge of noting down the suggestions for change from the staff. She would then share the feedback from colleagues with me and I would put everything together in one repository to use them in the analysis for the research. Moreover, we would discuss the evaluation and change feedback with the committee and the changes approved would be included in the new version of the prototype. 6 versions were launched during a 6 months period.

5.3.1.3 Follow-up Workshop with Healthcare Practitioners

After six months of testing and continuous evaluation, we decided to organize another workshop with the whole CRD staff. From the evaluation, we found that there were variations in how the staff members adopted the new goal plan. Thus, we wanted to involve them in critical reflections regarding their cooperation with the patient and how that cooperation was influencing patients' involvement, understanding, and control of the rehabilitation process. Moreover, suggest ways to improve the cooperation so that the patient could be more involved, understand, and control her/his own rehabilitation. My research aim was to have the healthcare practitioners elaborate their perspective on empowering practices and design of empowering artifacts for rehabilitation.

I planned and facilitated the workshop together with the OT from CRD. The workshop took place on the same day that it was a staff seminar for the whole unit. We were allocated 1.5 hours. The first part of the workshop was a summary of the redesign of the goal plan project till that moment. We then presented those parts that had been highlighted as positive with the new design and one area that was still not working, the connection between the weekly plan document and goal plan document.

We wanted to have the healthcare practitioners see the problems from the patients' perspective and what the patients needed to feel more empowered in their rehabilitation process. Hence, we created a patient persona that we called Maria (presented in Chapter 2). The overall idea is that Maria represents a typical case of a patient at Sunnaas. In addition to the persona, we created a goal plan for Maria and two weekly plans for the first two weeks that Maria had been at the hospital. Maria's goal plan showed that she had not used her goal plan during the stay.

The healthcare practitioners' first task was to think of why Maria did not use her goal plan. The aim here was to make the healthcare practitioners think critically about their position and possible contribution in a situation like this. We further asked the healthcare practitioners to think and discuss alternatives to the design that could motivate Maria to use this part of the goal plan document.

The third activity was related to the connection between the goal plan and the weekly plans. Participants were asked to look at Maria's next weekly plan and discuss how the weekly plan activities related to their specific domain could be made more visual and easier to understand for Maria. The idea was to make it easier for Maria to understand that one meeting in her weekly plan was related to one (or many) interventions in her goal plan. This would

Figure 5.6: Staff workshop for design in use

help Maria create health literacy because she knows that a specific activity can help achieve a specific goal. By putting the healthcare practitioners in the position to confront both documents at once aimed to contribute to increasing their awareness of the difficulty of making sense of both documents together from a patient perspective. Hence, the lack of understanding decreases the patient potential for participating in her/his rehabilitation and participate in decision-making with the healthcare practitioners.

There were 19 participants in the workshop. They were distributed into four groups. Three groups agreed to have a recorded session, and one group said that they did not feel comfortable. So the data collected were the three recordings, the workshop materials from individual work, and the group work. Figure 5.6 shows moments from the workshop.

Finally, I want to argued that such PD workshops resembled what Blomberg and Karasti (2012) define as design ethnographies Blomberg et al. (1996) presented above.

5.3.1.4 Additional activities

After the follow-up workshop, a new design of the goal plan was proposed together with some changes in weekly plans and additional documents that would support empowering practices in rehabilitation. These were taken further from the CRD management, but big changes were not implemented anymore. However, this served as a start for escalating the call for a digital version of the goal plan as an Information and Communication Technology (ICT) between a patient and her/his healthcare practitioners.

The CRD manager tried for other funding sources that could make possible the implementation of the new goal plan in the hospital's EMR, but we did not succeed. Moreover, the document and the research findings were presented in other divisions of the hospital, which took into consideration some of the findings that were more suitable for their patients. Until late, the discussion and communication with the CRD continued, and we also started on the Digital goal plan project that would be presented in detail below.

In June 2020, I participated in a meeting with the CRD. I was told that the people I had been working closely with during the redesign of the goal plan had taken the initiative to upgrade the document by removing and changing some parts. They stated that they created their prototype based on the research findings and inspired by the discussion regarding patients empowerment at the hospital enabled by the research. Thus, a new version of the goal plan document has been released at the CRU and is being used.

Aanestad et al. (2017, p. 45) have defined Participatory Continuing Design as "the continuing, user-driven, participatory process of working on completing the design of healthcare information systems after they have entered into ordinary use". To illustrate the work in participatory continuing design they discuss the process of videoconferencing design and implementation at Sunnaas stating that at Sunnaas "they have continuously redesigned their work by tailoring technology, adapting work processes, and attending to local needs and constraints" (Aanestad et al., 2017, p. 54). Even though the case the authors present has a bigger scale and scope, I want to argue that the project of continuing the redesign of the goal plan document after the new design was launched can be considered a participatory continuing design, where the staff is adapting processes and work around the document and also tailoring the document layout to represent the needs and constrains that emerged in use.

The authors (ibid) describe five ways in which participatory continuing research differs from design-before-use that is: timing, object, process, outcome, and participants. In the case of redesign the goal plan, the process has been going on for more than two years, the focus has been on services and work processes that will enable patient empowerment in managing the rehabilitation process. Both patient and healthcare practitioners are "living" with the document. Moreover, the focus has been on working configurations rather than layout functionalities and there is a genuine participation of users in the design while they use the document and provide feedback on it.

5.3.2 Research Block 2: A critical ethnographic study of the cognitive rehabilitation process in practice

In order to get to know better the rehabilitation process, I conducted an ethnographic study. How I applied ethnographic methods used is presented in detail below.

5.3.2.1 Non-participant Observations

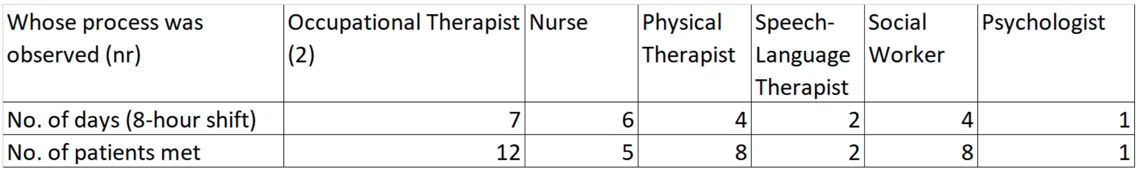
Non-participant observation is a qualitative method with roots in traditional ethnographic research. Its objective is to study phenomena in their natural setting of occurrence (Crang and Cook, 2007). As qualitative researchers, we presume that there will be multiple perspectives within any given community. We are interested both in knowing what those diverse perspectives are and in understanding the interplay among them. However, conducting observations is not easy. Several elements should be taken into consideration.

I used non-participant observations to investigate the rehabilitation process at Sunnaas hospital and outpatient clinique. The observations at Sunnaass were both for patients in their regular time of treatment at the hospital but also the follow-up week. I did not conduct participant observations in the municipalities as it was out of my scope. However, I still investigated that setting through interviews that I explain more below.

Regarding my observations at the hospital and outpatient clinic, I have presented an account in Paper II. I had initially in my study planned to shadow patients during their time stay at the CRD. However, with the CRD manager, we evaluated that shadowing a patient during the five weeks at the hospital might be overwhelming for the patient, especially the MACI patients that have, in most cases, issues of fatigue.

Moreover, we did not want to influence in any way the patient rehabilitation. We also considered that observing a couple of patient journeys would not give me an overview of the variety of rehabilitation journeys that patients have. So, we decided that I would shadow each of the roles of the health practitioners in the multidisciplinary team for a short period of time. This would minimize the stress of the patients and would give us the possibility to investigate the illness journey of more patients.

I shadowed two OT respectively for 4 and 3 working days (8 hours shift during the day shift because in the afternoon, most of the patients would go in their homes and no rehabilitation activities were planned at the department) and participated in activities with 12 patients, one nurse for 6 days and participated in activities with 5 patients, one Physical Therapist (PT) for 4 days and participated in activities with 8 patients, one speech and language therapist for 2 days and participated in activities with 2 patients, one social worker for 4 days and participated in activities with 8 patients and one psychologist for 1 day and participated in activities with 1 patient. A summary of observations in presented in Table 5.1 After each meeting with the patient I also asked the healthcare practitioners regarding the meeting to clarify the things that I didn't understand, evaluate the accuracy of my notes and also add additional things that I might had missed. I kept in mind the 5 why ethnography technique to pursue the real meaning of events.



Whose process was observed (nr)	Occupational Therapist (2)	Nurse	Physical Therapist	Speech-Language Therapist	Social Worker	Psychologist
No. of days (8-hour shift)	7	6	4	2	4	1
No. of patients met	12	5	8	2	8	1

Table 5.1: Summary of observations

The whole process lasted 6 months. There were days that I just went to CRD, and I sat in the "services room," as they call it – a room where usually nurses work, and I worked on documentation and observed the activities going on in the ward. In other cases, I went to the CRD because I had scheduled observation or a meeting, and that was canceled, so I used my time to get involved in conversations with healthcare practitioners and get to know more about their processes with the patients. I was also at the CRD for many days to work on the goal plan document. That helped to start becoming a part of the team as I was supporting the healthcare practitioners with possible problems with the goal plan document.

There is a difference between the number of patients that I met with each healthcare practitioner because the nurse and OT, and PT are involved in the multidisciplinary team of all patients at the CRD. Instead, the speech and language therapist is involved only for those with mild aphasia and in need assistance. The speech and language therapist was also involved in other activities at the hospital.

I participated in individual and group therapy sessions that a specific healthcare practitioner had with a patient or patients, and I also participated in staff meetings and staff discussions regarding patients and the way of organizing the services. Figure 5.7 shows a collage of pictures taken at the CRD ward. I have tried to capture the environment, and I have not taken pictures inside the patient rooms and in their meetings with healthcare practitioners.

At the outpatient clinic, I participated in two meetings that patients have there before they get their turn to be hospitalized.

During my non-participant observations, I took only handwritten notes that I wrote in my notebook while the event was happening or right after it when I had the possibility to note down. I transcribed the notes in the evening in digital ones with more extended accounts of the things I had observed. I assigned a code to each patient, and I used those codes to refer to the same patient if I met the patient twice.

Moreover, I also observed and kept notes regarding the cooperation and coordination of the healthcare practitioner I was shadowing with other team members, communication around the patients and tools they made use of for doing their work.

Besides handwritten notes, I also collected other data such as pictures from the department, documents that the staff would give to patients or documents that they used together with the patients, books and extended materials given to patients, and also some working documents that a healthcare practitioner used specifically in her/his own patient assessment or patient support. I was also given more detailed information on specific therapies and presentations that the healthcare practitioner used for group therapies. Hence, I tried to note everything relevant to the cooperative relationship between patients and healthcare practitioners during the rehabilitation process at the hospital.

I found that an important part was preparing the patient for the time home, so I paid more attention to that during the non-participant observations. Moreover, by observing sessions with patients that had come to the hospital

Figure 5.7: Some of the photos taken around CRU during my observations representing different activities in the department. Top right: myself dressed in hospital clothes. Middle top: notification of entertainment activities at the hospital. Top left: the dossier of the themes discussed in the group therapy called "Tema cafe". Middle right: the lobby area of the department. Middle left: one of the whiteboards used by the staff to coordinate work. Bottom right: one of the brainstorming sessions on the rehabilitation process with CRD manager. Bottom middle: A design from the OT leading the group therapy called "The cognitive group". The theme was the brain and its parts. Bottom left: the shelf in the lobby with games and books to be used by the patients.

for a follow-up week after 6 months of rehabilitation at home, I also learned about rehabilitative activities that the patient does while at home.

I was introduced to the staff at the CRD through the head of the unit. This makes it easier to open the door for research but makes it more difficult to gain the employees' trust. To gain trust I spent more time at the department sitting in the working room and even participating in the "Friday cake" event together with the staff. Additionally, I borrowed clothes from the hospital when I would observe meetings with patients and blend in the ward alo with my outfit.

5.3.2.2 Document Analysis

Another method that I used to understand the rehabilitation process was document analysis. I stated earlier that I was given a laptop at the hospital with a secure login to store my data. On this laptop, I had also access to the hospital's document system in which I could read more on processes and procedures and compare them later with what I saw in practice.

Moreover, at CRD, I could get real patients' goal plan and weekly plan documents. The documents were cleaned from any form of data that could relate to the patient. I reviewed 15 goal plan documents and approximately 50 weekly plan and also many other procedural documents. These documents helped me to understand more about the kind of activities at the hospital and how these activities were written in the two main documents that the healthcare practitioners used as coordination mechanisms with patients.

5.3.2.3 Interviews

Kvale (1983, p. 174), defines the qualitative research interview as "an interview, whose purpose is to gather descriptions of the life-world of the interviewee with respect to interpretation of the meaning of the described phenomena".

In the literature have been described three types of interviews, structured, semi-structures, and informal conversations (unstructured interviews) (Myers and Avison, 2002). In semi-structured interviews the interviewer prepares an interview guide with a set of general questions that want to ask and during the interview have the flexibility to add or remove questions based on how the interview is going. Instead, in informal conversations the interviewer has a main discussion topic, has any idea what to ask but does not make previously detailed preparation. I applied both.

Un-structured interview with the shadowed healthcare practitioner - With each of the healthcare practitioners that I shadowed, I also conducted a un-structured interviews. The things we discussed were: activities s/he does with the patient, how do they coordinate, where do they struggle, special cases of activities. I also asked regarding her/his role in the goal setting and how s/he sees patient empowerment for the patient and also her/himself contributing to the patient empowerment. I used handwritten notes to write down the answers. In total there were 7 interviews. Each approximately 30 min, even though I don't have recordings and an accurate time for such interviews.

Semi-structured interviews at the municipality - The way how rehabilitation services are organized in different municipalities in Norway varies a lot. The Indre Østfold region is currently carrying on an Innovation Rehabilitation project (Eide et al., 2017; Fuglerud et al., 2018). The project aim is to offer better rehabilitation services that would centralize around the "person" (a very important concept for the project - as one of the interviewees said, *"at the hospital there are patients, here in the municipalities we have persons, which besides the illness have as well a life"*) and offer integrated care. Moreover, unify the services in the seven communes that are part of the project. Their person-oriented approach and the aim of integrating services so the patient can get "the full package" are considered as best practices scenario.

Considering their high expertise in the organization of rehabilitation services in municipalities, I initially conducted a semi-structured interview of 2 hours with two of the project initiators to get an understanding of their way of working within this project, but also investigate and learn from their experience in the field how the rehabilitation process was organized in other municipalities.

I also met with the project manager and the person in charge of the operations to investigate the rehabilitation organization more in detail. The meeting was organized as a semi-structured interview where I was presented with their way of working and the patient journey for them, and I was asking investigative questions to capture even more details. I recorder both interviews and transcribed them later. The second interview also lasted approximately 2 hours.

Semi-structured interviews with patients - I had three interviews with MACI patients to ask about their illness jorney, life with the disability and their rehabilitation process. The interviews lasted each 30 min and were conducted at each patient's room at CRD. Staff at the CRD helped me to schedule such meeting and recruit the patients.

5.3.2.4 Researcher's Reflective Notes

Throughout my research, I have kept notes (in total 7 notebooks) in which I used to write down every thought and idea regarding my PhD. I am keen on visualizing my thoughts (even though I am not a good sketcher), and I have used this way to be involved in a continuous reflective analysis regarding my research while I was going along with activities.

Moreover, I have also logged in my notebook interesting concepts from the literature and tried out different conceptual schemes to make sense of my understanding of the data I was gathering.

These notes have been very relevant for each of the papers that I have published and for this thesis. I have returned to them many times as memory logs of my thinking process and to see how my visualization of findings has evolved in time. These memory notes have helped me go to the core of some of my ideas or literature that I had not made use of in the individual papers but contribute to this thesis's development.

5.3.2.5 Log-Reports

I have been keeping minutes of meeting for every meeting that I have had with Sunnaas staff. The length of reporting varies from one meeting to another, but I have tried to keep track of all the relevant things contributing to my study. I used to write notes directly on my laptop of quotes and relevant information during the meeting, and then I used to expand the notes once I went home in the afternoon. Usually, in such meetings, we could be engaged in designs and schemes on whiteboards. I have documented these with pictures which I have attached to the notes.

Of major relevance are some of the workshops' preparation meetings with the project committee or the OT at Sunnaas that have worked closely with me during my research. These notes have been relevant for reflecting on the MACI people empowering practices in co-design.

Another relevant source of information has been the meeting with the IT representative at Sunnaas, especially for the project that would be explained in Research Block 3. The meeting notes have been relevant in the analysis and provided insight into the design characteristics for empowering artifacts in rehabilitation. The meetings mentioned above were mostly arranged as brainstorming sessions.

5.3.3 Research Block 3: The digital goal plan

The aim of this research project was to design a digital cooperative artifact. The artifact was to be used between patients and healthcare practitioners in rehabilitation to support the rehabilitation process's management. This is part of "VITAL - för den goda hälsan" project, financed by the INTERREG Sverige-Norge under the grant number: 20202391. Both Sunnaas and HiØ are partners in this project. The aim of the VITAL project is to promote the involvement of Small and Medium Enterprises (SME) in developing healthcare services and digital solutions in Norway and Sweden. HiØ and Sunnaas are participating together in a small part of this project. The project is planned in two parts: design and development, where HiØ will do the design in collaboration with Sunnaas, and for the development, an external company will be employed. I report in this thesis activities related to the design of such a solution.

I applied a PD approach to design the digital goal plan and to investigate empowering practices that the design could enable. I had already finished my ethnography study, and I had been involved in co-design with patients and healthcare practitioners separately. Thus, to perform a proper PD project, I decided to involve both MACI patients and their healthcare practitioners at the CRD in co-design workshops. The workshops aimed to engage patients and healthcare practitioners in discussing and negotiating their cooperation and defining characteristics of the cooperative artifacts to support their needs and wished for cooperation. So, while the theme was the design of the cooperative artifact, the design aim was to understand more about the work practices related to it.

However, such co-design workshops contributed also to investigate practices and artifacts that would support to balance powers in the co-design sessions between MACI people and their healthcare practitioners. Drawn in the literature, I developed a method for supporting MACI patients in co-designing cooperative artifacts with their healthcare practitioners. I applied the method in the two workshops and analyzed if the method had contributed to empowerment outcomes in co-design: have a say, influence decision-making, and influence the design result.

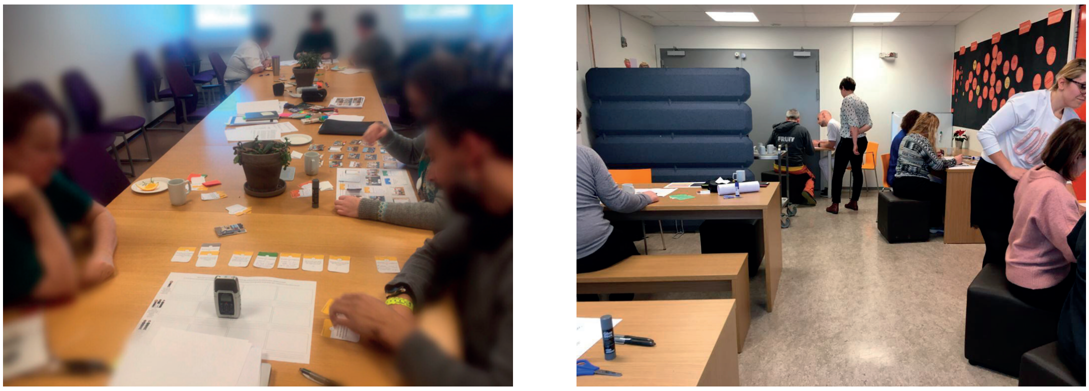
The method and the application of the method is presented in detail in Paper V. The method is called "Equilibria Nudge" or short EquiN. I present the method in Chapter 6 as part of my findings.

5.3.3.1 EquiN Workshops

I applied the EquiN method in two workshops with patients and healthcare practitioners, both involved in the workshops.

The first workshop was focused on investigating the practices' and artifacts' functionalities for the part of rehabilitation from the moment the patient was accepted to the hospital until the rehabilitation plan was created. The second workshop focused on the rest of the rehabilitation process related to the implementation of the rehabilitation plan and the dynamic cooperation between the patient and healthcare practitioners.

In the first workshop, participated 2 patients and 3 healthcare practitioners. Instead, in the second workshop, participated 5 patients and 5 healthcare practitioners. The workshops were organized respectively, 22nd of January and 5th of February 2020 at Sunnaas premises with patients with MACIs and staff from the CRD. Each of them lasted approximately 1.5 hours.



(a) Workshop 1

(b) Workshop 2

A detailed description of the workshops is presented in Paper V, and a general description of the layout of the workshop is presented in Paper III. Here I introduce a short version of the activities in the workshops.

The workshops had two parts. In the first part, two parallel sessions ran. One session with MACI patients and another one with healthcare practitioners (called horizontal sessions). Both groups were provided with some cue cards that we have called in Paper V, EquiN cards. The EquiN cards were paper cue cards that included some possible statements of design ideas for functionalities of the cooperative artifact to be designed. Participants had to initially evaluate the statements in the cards individually. They had to decide which functionalities represented in the cards they wanted to have in the digital goal plan. Then they had to share their choices with the rest of the group.

Finally, after all had introduced their choices they had to discuss as a group which ideas were the most relevant for the group and select in consensus 5 main design ideas. Participants were encouraged to change the statements, add, remove, or design over.

The EquiN cards and the statements they contained were inspired by the ethnographic study and an understanding of the rehabilitation process. The statements were vague and not clear suggestions. They represented specific moments and activities during the rehabilitation process as a way to be a nudge for the participants to discuss parts of the process and their needs and requirements for a digital cooperative artifact.

The second part of the workshop included parallel sessions of one patient - one healthcare practitioner (called the vertical sessions) involved in co-design activities. The patient and the healthcare practitioners had to bring the EquiN cards selected in the horizontal group with them in the vertical groups. They were then asked to create a storyboard that would show how each of the functionalities they had selected could be implemented in the rehabilitation process practices at the hospital. Besides the EquiN cards, each vertical group was given a storyboard template, structured in activities the patient does alone, activities they do together, and activities the healthcare practitioners do alone. Moreover, they were given pictures as cue cards to represent the interactions in practice (animations from patient rooms, animation from meetings in the corridor, etc.) and make up the storyboard.

Both workshops were recorded, and the records were then transcribed. The workshops were in Norwegian, so the quotations from these workshops are a translation of what was said. Additionally to the recording, I took pictures and also saved all the workshop materials from each part of both workshops. Moreover, I received from the practitioners a description of the diagnosis for each of the patients. No names were mentioned. We assigned some random numbers. Also, I received the patients' goal plan and weekly plans documents to analyze their rehabilitation journey at the hospital. During the workshops, I also noted down which patient was in a vertical session with who from the healthcare practitioners, and I notated if the healthcare practitioner was one of the patient's direct healthcare practitioners or not.

For recruiting patients, I relied on the CRD staff. We discussed beforehand that the group of people should be as representative of the patients at the department as possible. For the staff, I had representatives from different domains of the multidisciplinary team. We were two facilitators in both workshops. Again, I was joined to facilitate the workshop by the same OT I have been collaborating with throughout all my research. We were both involved in the planning process of the workshops and also in co-facilitating. During the horizontal sessions, we sat each with one of the groups. I facilitated the session for the healthcare practitioners, and the OT facilitated the session for the patients. Instead, in the vertical groups, we were going around from one group to another to provide support. In the second workshop, where we had 5 vertical groups, it was challenging to coordinate. We had a third facilitator in charge of distributing the workshop materials and taking pictures.

The vertical sessions exposed more needs regarding empowering practices in rehabilitation and also characteristics for empowering artifacts. Moreover, the workshops contributed to reflecting and analyzing the power relations between MACI patients and their healthcare practitioners in the vertical groups and how the EquiN method drawn in theory contributed to balance powers in the co-design.

5.3.4 Research Block 4: A systematic literature review on PD with people with cognitive impairments

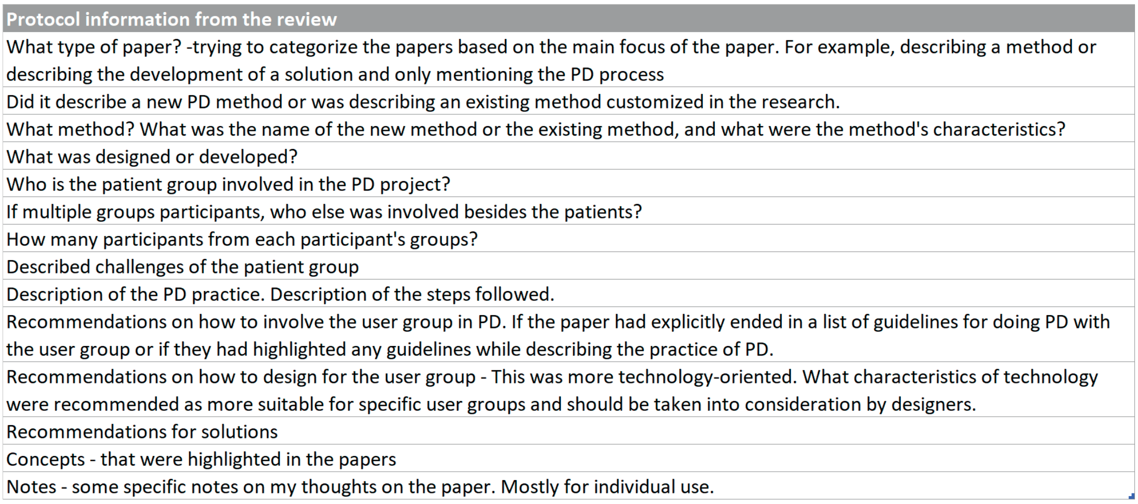
One of my research interests is to empower people with MACI in co-design sessions. While there has not been much research in PD specifically with this category of users, there has been a lot of research in PD with other user groups who share some similarities in symptoms with MACI people. In order to gain better knowledge of how to make MACI people have a say, influence decision-making, and the design outcome in co-design, I conducted a systematic literature review on PD with people with cognitive impairments.

Systematic literature review is defined by Okoli and Schabram (2010, p. 1) building on Fink (2019, p. 3) as "a systematic, explicit, comprehensive, and reproducible method for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars, and practitioners."

Okoli and Schabram (2010) define some steps for conducting a systematic literature review. I use these steps to present how I conducted my literature review.

Purpose of the literature review - The reason to conduct the systematic literature review was to create knowledge on how to involve MACI people in co-design by building on others' experiences, guidelines, or different techniques and tools that they had used.

Protocol and training - the literature review's aim was clear, and from the start, I had determined that I wanted to make a comprehensive review of the literature that could be analyzed from different perspectives. So, I had the following categories in my protocol as listed in Table 5.2



Protocol information from the review
What type of paper? -trying to categorize the papers based on the main focus of the paper. For example, describing a method or describing the development of a solution and only mentioning the PD process
Did it describe a new PD method or was describing an existing method customized in the research.
What method? What was the name of the new method or the existing method, and what were the method's characteristics?
What was designed or developed?
Who is the patient group involved in the PD project?
If multiple groups participants, who else was involved besides the patients?
How many participants from each participant's groups?
Described challenges of the patient group
Description of the PD practice. Description of the steps followed.
Recommendations on how to involve the user group in PD. If the paper had explicitly ended in a list of guidelines for doing PD with the user group or if they had highlighted any guidelines while describing the practice of PD.
Recommendations on how to design for the user group - This was more technology-oriented. What characteristics of technology were recommended as more suitable for specific user groups and should be taken into consideration by designers.
Recommendations for solutions
Concepts - that were highlighted in the papers
Notes - some specific notes on my thoughts on the paper. Mostly for individual use.

Table 5.2: The categories of review notes

Searching for the literature - I conducted my search in two main databases ACM and Springer. This because ACM and Springer are the publishing venues of most of the conferences and journals in design. I initially planned to look into publications in specific conferences. However, in order to not risk leaving out any relevant publication, I decided to expand the search generally for the two databases. I used several search terms in both databases. The first search term was “participatory design” or "codesign" (and variations of it), and as a second search term, I searched more specifically for those user groups that experience cognitive impairments such as "older adults", "dementia", "aphasia", "cognitive decline", "brain injury", and "stroke". Moreover, I added search terms that relate to the symptoms that people with cognitive impairments face, such as "memory", "attention", and "tiredness". This gave me an extensive set of papers. In ACM, there were, in total, after removing duplicates, 326 articles and in Springer 146. I also researched the database of Participatory Design Conference (PDC) proceeding up to 2002 and found one relevant paper.

Practical screen and Quality appraisal - I did both steps at once by doing an initial screening and deciding on those papers that needed to be included in the review. In the first screening of the papers, I read the abstract and did a screening of the paper’s structure. I removed as out of scope all those papers that were focused on technology development and had only mentioned PD once in their method to describe how the design had been. Another category removed was papers that described research on other user groups not relevant to the study. So every paper that did not describe a PD practice with or for people with cognitive impairments was considered out of scope, and in the paper type, I classified these with (O). I had retrieved the lists from both databases in Excel, and I did the first classification in Excel.

After the first screening, I was left with 38 Springer papers and 107 ACM papers to read in detail in the second round. I merged the Excel databases into one and started the second round of detail analysis and note-taking for each paper. Meanwhile, I had downloaded the papers on the first screening once I had decided the paper was going on for further reading. Differently, from the proposal of Okoli and Schabram (2010) I did not assign quality points to articles as the description of the PD practices is difficult to rank. However, as I stated earlier, I noted the number of participants included and also the practical activities of PD, and the number of iterations of using the methods. This helped me later when analyzing the findings.

Data extraction - This was done based on the protocol fields, as mentioned above. The "type of paper" field was a fundamental categorization from the start. It also worked as a quality mechanism because it was more relevant to review those papers that had the method described as their main focus. Instead, the papers focused on application description had a comprehensive description of their PD practice, and that is why the PD practice field in the review notes was more relevant to analyze further. Even in this round, some more papers that were defined as relevant on the first round were reassigned as out of scope.

I concluded the selection with 105 papers. The classification of the papers that I made was: Technology papers (18); Methods papers (49); PD practice papers (28) - in which both the PD process and the tool developed were explained but without aiming theorizing; and General PD challenges papers (17) - focused more in a conceptual discussion of what implications and what concepts are important on co-designing with people with disabilities. It should be emphasized that it was not a clear cut between the categories, and some papers could belong to all. However, I decided on the category based on the paper's main contribution. Meanwhile, in all the other fields, I paraphrased the paper or directly quoted some parts of it.

Okoli and Schabram (2010) describes two more phases relevant to the systematic literature review that relate to the analysis and reporting of the review. I explain how I did this in the Analysis subsection.

5.3.5 Analysis Methods

Myers and Avison (2002) addresses three modes of analysis: hermeneutics, semiotics, and narratives and metaphors.

Hermeneutics is primarily concerned with the meaning of a text or text-analogue data, and is based on interpretations. Semiotics refers mainly to the "meaning of signs and symbols in language". The essential idea is that words/signs can be assigned to primary conceptual categories, and these categories represent important aspects of the theory to be tested. Instead, narratives and metaphors refer to stories.

The type of data that I have collected involves mainly text and also some more visual representation from workshop materials which can be turned into text in their explanation. The analysis of data for answering the research questions in this thesis is more compatible with hermeneutics as a mode of analysis. However, when interpreting data, coding, and categorizing, I have paid attention to language signs and symbols in order to adapt the symbols to the interpretation of my material. Hence, I would position my analysis in the hermeneutics, interpretive analysis with a special focus on the signs and symbols used as themes for such interpretations. Moreover, the hermeneutics and semiotic mode on their own have prevailed in different parts of data analysis and in different papers. I will elaborate below on the methods that I used for analyzing my data.

The analysis of data regarding rehabilitation has been conducted in close collaboration with Sunnaas representatives, or it has been cross-checked with Sunnaas representatives. Instead, the analysis of data regarding MACI patients' empowerment in the design process was initially analyzed individually and later cross-checked with my co-author and PhD supervisor Harald Holone.

5.3.5.1 Reflective Analysis

To analyze the experience of conducting PD with people with MACI, I build on Schön (1983) approach of the reflective practitioner. Schön describes two types of reflections that practitioners experience:

Reflection-in-action - undertaken in the indeterminate zones of practice. The reflective practitioner "thinks up and tries out new actions intended to explore the newly observed phenomena, test tentative understandings of them, or affirm moves invented to change things for the better. What distinguishes reflection-in-action from other kinds of reflection is its immediate significance for action." (Schön, 1983, p. 28-29)

Reflection-on-action refers to the process of making sense of an action or event after it has occurred. It serves to extend one's knowledge base. I have used both types of reflection on the workshops in Research Blocks 1 and 3. While the reflections in action are individual and are related to knowing in action, the reflections on action happen after the event. I have also noted or recorded (in some cases) the reflections of the second facilitator participating in the workshop.

I have applied reflection analysis on the empowering practices and artifacts for co-designing with MACI people. I used a systematic approach to conduct reflections. I was immediately after the workshop documenting my reflections-on-action. As we were two facilitators in the workshop, we sit together to reflect on different aspects of the workshops after each of them. On some occasions, I have recorded our reflections and revised them later. In some others, I kept handwritten notes documenting what each of us had observed or noticed in the workshop. Schön (1983) relates the reflections with the designer as an individual process. I found the shared reflection-on-action very useful to bring to my attention things that I might have missed reflecting on my own. Moreover, the shared reflections helped me avoid the mistake of having a subjective approach to reflections.

Another technique that I used to structure my reflections was to look at the literature for conducting PD with people with cognitive impairments and compare the findings with my initial list of reflections. I used a "reflective interpretive correlation analysis". Reviewing the theory and comparing it to my reflections helped me to expand my reflections. It made me reflect and highlight things that I had taken for granted. For example, in my initial list of reflections-on-action, I had not reflected on the environment's role in the participants' behavior. The rooms in which I had the workshops were all familiar places for the MACI participants. One of the patients in the redesign project in the second workshop had commented on this. Finding the right room and a known environment had been mentioned as a best practice in the literature.

This helped me reflect that, indeed, that had been the case with my participants as well. I added this reflection to my reflection list. I compared my empirical data reflections from conducting PD with MACI people and the list of guidelines drawn from the literature review to conclude a list of guidelines for PD for MACI people. I used MS Excel to conduct such analysis as shown in Figure 5.9. In the first column, I have listed the findings from the literature review. In the horizontal top row, I have listed my reflections-on-action based on the empirical experiences. I grouped my reflections-on-action in categories similar to the one of the literature review and then compared the findings for

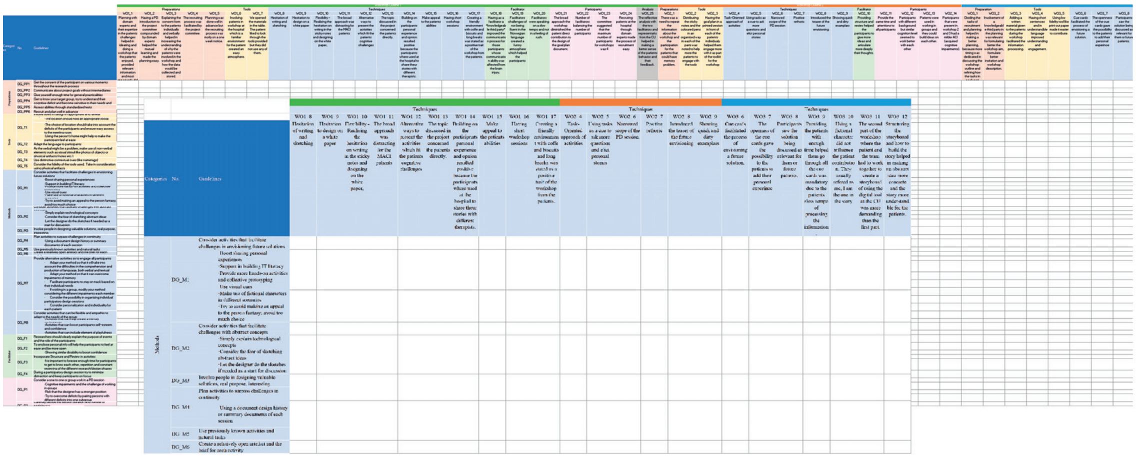


Figure 5.9: A picture of the reflective interpretive "correlation analysis" between the empirical reflections and guidelines from the literature review

each category. In Figure 5.9, the central part shows the "Techniques" category.

5.3.5.2 Discourse Analysis

Discourse analysis is also a method in which we retrieve meaning from a dialog. Discourse analysis is used to make sense of data in conversation and assign meanings to parts of conversations. The discourse analysis is a suitable method for capturing the moment-to-moment snippets of conversation and analyzing and interpreting them within a specific context (Wooffitt, 2005).

In my thesis, discourse analysis was used to analyze the workshops' recordings from the digital goal plan project. The aim was to analyze if the patient had influenced the decision-making and the design outcomes during the vertical groups once EquiN method was applied. A detailed description of this process is presented in Paper V.

As the discourse analysis unit of analysis, I used the conversations for each of the EquiN cards. I initially located all the parts of a conversation in a vertical group related to a specific card. I did so for each card and for each vertical group. So, in total, 50 conversation snippets (I had in total 7 vertical groups with 5 cards from the patients and 5 cards from the healthcare practitioners in each group. Two of the vertical group recordings were not possible to transcribe as the recorder had not worked properly. So, I had to rely on 5). Then, I focused on interpreting the conversation into discussion bubbles. I developed the discussion bubbles based on the number of sentences each participant had said in the discussion on that specific card. Then, I analyzed the whole conversation and interpreted who had decided how to involve the card in the storyboard. Further, I analyzed the discussion bubbles and who had made the final decision for all the 50 conversation snippets, and I finally grouped them into categories of decision-making types.

In Myer's living version "Qualitative Research in Information Systems![2], discourse analysis is listed under semiotic analysis modes. The discourse analysis helped me assign signs to conversations, such as the discussion bubbles and who made the design decision. However, I also had an extensive process of interpreting the conversation in order to assign specific codes to each piece of the conversation. Hence, I applied a hermeneutic model of analysis and in the last part closer to a content analysis that I present in the following subsection. I conducted the analysis manually.

5.3.5.3 Content Analysis

Content analysis is a method of analyzing written, verbal, or visual communication messages (Hsieh and Shannon, 2005). There are two ways to conduct content analysis, inductive where the data analyzed leads to the definition of categories, which then can be grouped into bigger topics called themes. The other approach is deductive, where a set of previously defined categories or themes that come from the literature or previous research will be used to categorize the material gathered (Mayring, 2004).

Overall, the process of data analysis includes the following core steps: selecting the unit of analysis, creating categories, and establishing themes. Selecting the unit of analysis is an important initial step as a means to reduction. Researchers should decide which data will be analyzed by focusing on a selected aspect of material depending on the research questions.

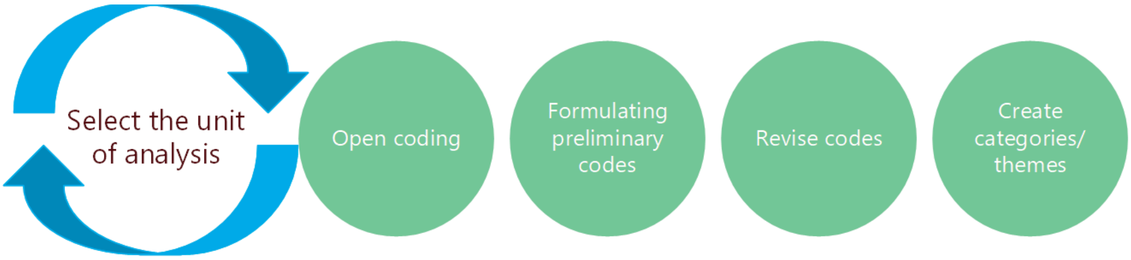


Figure 5.10: My version of content analysis activities. Adapted from Cho and Lee (2014, p. 11)

In Figure 5.10, I have presented my version of conducting the content analysis. I have applied content analysis in different parts of my research. I had different units of analysis to start with and different aims for the content analysis. The rest of the process has been the same as presented in the figure.

I applied content analysis to defining empowering practices for patient empowerment in rehabilitation. The data to analyze were the ones collected in Research Block 2 and also workshop recordings and workshop materials from Research Block 1 and 3. I started by open coding the data in terms of practices that had been mentioned in workshops as relevant for empowerment. I started formulating categories for the practices. I had three main categories initially. I

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[2] https://www.qual.auckland.ac.nz/

used these codes and categories to analyze also findings from the ethnography study. Some of the codes were revised, and others were added, concluding in six categories. I had defined empowerment in rehabilitation as happening in the cooperation space between patients and healthcare practitioners. So, in the final round of my data analysis, I revised the categories through CSCW concepts lenses and concluded in six main themes that I present in Chapter 7 as practices for patient empowerment in rehabilitation.

I conducted the same procedure of open coding and categorizing for defining implications for design for empowering artifacts in rehabilitation. Unlike the practices, I apply the CSCW concepts lenses to critically reflect on the conceptualization of such artifacts and the role they would play in the cooperation to enhance empowerment.

Moreover, I applied inductive content analysis to analyze the literature review data presented in Research Block 4. I open-coded the data initially. Then I applied apriori categories inspired by a previous similar literature review by Hendriks et al. (2013). I revised 2 of the 7 category names. I used NVIVO[3] as my supporting tool to conduct content analysis for the literature review. NVivo is a qualitative data analysis (QDA) computer software package. It supports qualitative researchers to organize, analyze and find insights in unstructured or qualitative data like interviews, open-ended survey responses, journal articles, social media, and web content, where deep levels of analysis on small or large volumes of data are required.

5.4 Ethical Considerations

As stated above, the project is a joint initiative with Sunnaas Rehabilitation Hospital.

As the research implies sensitive data regarding patients from Sunnaas rehabilitation hospital, my supervisor at Sunnaas, Frank Becker, in the role of the project manager, initially sent the project description at the "Regional komité for medisinsk og helsefaglig forskningsetikk REK sør-øst-Norge (REK) - translated as "The committee for medical and health research ethic - to ask if we needed to send an official application to REK. The committee replied that the project “can be carried out without REK approval” considering the focus on the work processes and not the medical side of rehabilitation.

We were further recommended to clear our research with the “Personvernombud for andre virksomheter” (translated as "Privacy representative for other companies") situated at the Sunnaas Rehabilitation Hospital. “Personvernombud for andre virksomheter”, is the data clearance entity used specifically for medical research in hospitals. Within weeks we got a positive response, and we were good to go with the research.

All the sensitive data collected was agreed to be stored at Sunnaas premises. Regarding electronic data, Sunnaas has a research folder where all the data from individual projects should be stored. I was given access to that research

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[3] https://www.alfasoft.com/no/produkter/statistikk-og-analyse/nvivo.html

folder. Moreover, I acquired a dedicated laptop from the hospital through which I accessed the research folder and stored the electronic data. In order to work on the data from home, I have been granted access to Sunnaas network over VPN.

Paper documents called during the research are stored in locked storage at Sunnaas. To record, take pictures and videos, I used external recorders and a camera that was not connected to the internet. The recorder was provided from Østfold University College, and the camera belonged to the PhD candidate. The data was taken from this equipment right after the event, stored on the Sunnaas laptop, and deleted permanently from the equipment.

Moreover, the information exchange with theCRD staff was organized through the Sunnaas email for sensitive information and email services provided by the Østfold university college when the data was not sensitive.

The data analysis was digitally performed at the Sunnaas laptop, and findings were saved in the research folder. Regarding other ethical dilemmas I had during my research, I have continuously consulted with my supervisors at the HiØ, University of Oslo (UiO), and Sunnaas to ensure proper safety of data. Moreover, we have evaluated in each step if there was a necessity to ask the Privacy Representative.

All participants in the research signed a consent form. In the consent form, participants were provided with all the relevant information concerning their participation and intention for using the data collected during the study and disseminating the information. It was clearly stated in the consent form that each participant had the right to withdraw from the study at any given time. I wrote the consent form both in Norwegian and English in order to make it easier for all the patients to have the possibility to participate.

I did not keep a record of any sensitive information for the patients or the staff members. Instead, I assigned self-made codes to make sense of where the data was coming from in my analysis. Most of the data collected are anonymous. The only identifiable data are the audio recordings stored in the hospital's digital safe location.

In the papers and this thesis, I have used codes to refer to the participants. Moreover, I have not involved any quote that would expose any personal information for the patient, creating a risk for identifying her/him.

5.5 Self-reflections on my position during research

> "It is necessary for researchers and designers [. . .] to be able to reflect upon not only activities in the design process but also upon the multiple intentions and interpretations that build the analytic lens of the research or design project." (Mörtberg et al., 2010, p. 107)

The interpretation and analytic lenses can be influenced by the researcher's positionality in relation to the research and the personal background that influences the way the researcher sees the world. I have described above that my research project was ideated before I joined the team. I had the possibility to customize my research proposal and focus both on issues of interest for Sunnaas and for me and my research interest. However, this is not the right way to go in empowerment, as empowerment movements should initiate from those groups of people who feel the necessity to change their situation.

Once starting my study and being engaged in activities with patients and healthcare practitioners at Sunnaas, I realized that the call for empowerment was supported by patients and healthcare practitioners even though Sunnaas representatives had become the ones to prompt their voice. In the first section, I provided an overview of my background that shows my interest in democratic and cooperative relations as a way to empowerment. Here, I reflect on my position as an ethnographer and as a thoughtful facilitator in PD workshops.

Reflecting on the "myself" during my research

I chose a PD and ethnography approach for my research and also conducted some activities of what is defined as design ethnographies. In the following paragraphs, I present my reflections regarding a) only myself and b) me and the participants in my research in relation to each other. Blomberg and Karasti (2012) emphasize the relevance of reflexivity in ethnography as a way to make explicit the factors that could influence what the ethnographer sees and how that is portrayed to her/him by the objects of research.

When conducting non-participant observations, I spent quite an extensive time at the hospital. During this period, the most challenging part was to merge with the staff and to make them feel comfortable to have me around and still get engaged in the same interactions with one another and with the patients as without my presence. I had an objective approach toward the things that I observed, but I can not tell how that objective representation of reality would change without my presence there. In my observation notes, I write about the struggle I faced in remaining invisible in the meetings between a patient and a healthcare practitioner in a room with only us three. In order to blend, I also took on the healthcare practitioner's clothes.

Moreover, when conducting my observations, I continuously tried to set apart my interest in patient empowerment and the necessity to increase the patient understanding and control on the rehabilitation process, and focus on the situation and describe that in detail as it was. My lenses of empowerment would be set later in the analysis.

However, my struggle between my aim focused on change and reporting the situation as-it-was, it was not only mine. It also was the way how the healthcare practitioner saw me. I started my study at the CRD by being involved in redesigning the goal plan to achieve patient empowerment. This was the way I was introduced to the CRD staff. Hence, I was for them also the designer, the interventionist involved in the redesign of the goal plan. These internal struggles were also manifested in the way I was viewed back. I think that has influenced the conversations I had with healthcare practitioners.

Instead, on the patient side, I was another person in the multidisciplinary team that had an interest in researching the rehabilitation process. Thus, my double role was not a problem. Instead, with healthcare practitioners, I think that the designer-ethnographer role has contributed to making them reflect on their work processes and how their cooperation with the patient contributes to patient empowerment.

Blomberg and Karasti (2012, p. 38) state, "reflexivity requires that we acknowledge how such things as personal histories, particular relations between ethnographer and study participants, debates within academia, and broad sociocultural circumstances affect the outcomes of the research." I was having the above reflections and conversations with myself while in action and conducting my observations (as also recommended by Schön (1983)).

My design findings from the redesign project were somehow influencing my focus on things during the ethnographic study. In some cases, this was positive as it would bring to my attention things that I could have missed. Moreover, it provided me with more knowledge that I used to engage with the healthcare practitioners and ask them more questions about their interaction with the patients.

I also had the role of the designer in my research. Blomberg and Karasti (2012, p. 39) on reflexivity in PD state "Some have argued that PD researchers while focusing on technology and users have missed the opportunity to make visible the ‘self’ or their particular knowledge, agency, and responsibilities in addition to their relationship to the study participants and the overall project outcomes". Reading through my papers about PD with MACI people, I find myself in the quote. I describe my position in design workshops as the facilitator, and I do not present much reflections on my self or my position, biases, behavior, and influence in the design process. From the description of my role, I seem to run in the background preparing everything, explaining tasks, providing support, and trying not to influence the design space. That is not only how I describe myself, but it is also how I was aiming to be in the process, a facilitator.

However, even though not a main character in the design workshops, I have been ideating the workshops, practices, and artifacts used. To learn more about the patients and support me in creating the right environment for MACI patients, I have cooperated with a domain expert at Sunnaas, an OT. The workshops’ planning has been based on knowledge from the literature and based on my co-worker’s experience in the rehabilitation process. I have been involved continuously in reflections of my influence on the outcome of the design. Thus, I have tried to use previous encounters with patients to ideate the next steps.

The use of the EquiN cards could become a big sphere of influence as the initiation of the statement came by us as the facilitators. However, the statements only represented different activities in the hospital that I learned during my observations. The statements were general and vague. The aim was to serve as a nudge for patients and let them make up their interpretation of such statements. From my analysis and reflections on such a situation, the patients were not influenced by our ideas. They instead picked up on some main words and provided more personal interpretations.

Finally, being a designer and ethnographer is challenging. I had to continuously remind my self the aim of a specific part in the research activities. However, despite my own self-reflexivity, I also considered the way the others (in my case, the healthcare practitioners) that observed me back in this position would change their behavior and influence my data collection.

Part II

Part II - Findings

CHAPTER 6

PRACTICES OF EMPOWERING MACI PEOPLE IN CO-DESIGN

> "He who completes a quest does not merely find something. He becomes something."
>
> *Lev Grossman*

Outcomes and findings regarding co-design with people with Mild Acquired Cognitive Impairments (MACI) and their empowerment in the co-design process of cooperative artifacts that they can use with their healthcare practitioners are presented in this chapter. Only three out of the seven selected papers in this thesis are directly related to the findings presented in this chapter and contribute to answer RQ1 - *What practices contribute to Mild Acquired Cognitive Impairments (MACI) people empowerment in co-design?*

In Chapter 3, drawn in the literature, I argued as empowerment outcomes of a user group in co-design - *having a say* during the design process, *influencing the decision-making* and the *outcome* of the design process. To achieve empowerment outcomes, empowering practices should be implemented. Moreover, empowering artifacts can be designed to facilitate empowering practices and promote empowerment outcomes.

In this chapter, I present my findings regarding the practices and artifacts that a researcher or designer can apply to facilitate empowerment outcomes for MACI people when involving them in the co-design process of cooperative artifacts that they can use in cooperation with other user groups. I have studied the co-design of cooperative artifacts that MACI people can use to coordinate their cognitive rehabilitation process with their rehabilitation healthcare practitioners in a rehabilitation hospital. As stated in Chapter 5, the answer to RQ1 is constructed theoretically and empirically. So, I have used theoretical knowledge rooted in previous literature on doing Participatory Design (PD) with people with cognitive impairments and experimented with PD workshops with MACI people.

Taking a PD approach to design a cooperative artifact implies involving in the co-design process every interested group that would be affected by the cooperative artifact. To design cooperative artifacts for MACI people they need to be involved in co-design with the designer and the other relevant stakeholders for the cooperation. In the case I have studied and I am interested in, such other stakeholders are the healthcare practitioners of a rehabilitation hospital.

A relevant principle in PD is equalizing power relations. This starts by recognizing and becoming aware of power issues between participants. In MACI people-healthcare practitioner relationship in co-design sessions, some factors can create a dis-balance in powers. First, co-designing requires a certain level of cognitive abilities. Thus, MACI people might face challenges due to their cognitive problems. Second, power issues exist due to the healthcare system's structural hierarchy, where the healthcare practitioners provide care and the patient (in my case a MACI person) is the one suffering that needs care — often defined as resembling a paternalistic relation. Third, there are differences in power/knowledge regarding the management of the care process. The patient is an expert in her/his condition, and her/his knowledge is added value in the care process. However, healthcare practitioners have a better overview of the care process's management (they have followed many patients in their journeys).

When negotiating cooperation in the rehabilitation process management, healthcare practitioners will be favored because they know the process, compared to the patient who is getting to know it by experiencing it. This luggage on the MACI people side creates a disbalance in power between MACI people and the healthcare practitioners when involved in co-design with one another. I have visualized this disbalance in Figure 6.1. I address these disbalances through my study and describe practices and artifacts that can help lift MACI people in the co-design space and create an equilibrium with the healthcare practitioners. In Chapter 4, when presenting the concept of power in PD, I distinguished the power issues on the overall decision-making of a PD project (such as in the case of Bratteteig and Wagner (2014)) and in the micro-power relations, referring to the power games in PD sessions where different stakeholders are involved. These micro-power relations are of my interest and where the empowering practices and artifacts described in this chapter influence.

In Zimmerman and Warschausky (1998) empowerment theory , individual empowerment was considered as closely related to organizational empowerment. An individual is empowered when s/he becomes aware and perceives control in relation to the others with whom s/he enters in relation in the organization. The applies also for MACI people in a co-design process. The practices of empowering MACI people in co-design imply increasing their abilities to co-design and use these abilities in co-design sessions with others

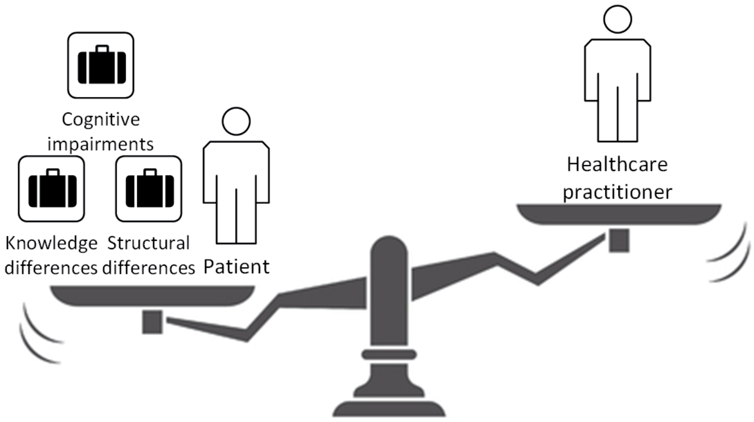


Figure 6.1: A dis-balance in power between the patient and the healthcare practitioners

to influence decision-making and design outcome.

The findings summarised in this chapter have been presented in Paper III, IV, and V included in this thesis. I initially introduce the papers. Then, I present a more detailed account of my findings regarding empowering practices for the empowerment of MACI people in co-design individually and in relation to their healthcare practitioners. I conclude by discussing some empowering artifacts that I have found useful in my research to support the empowering practices.

As I have also highlighted in the papers, my findings of practices and artifacts are co-constructed with participants. I do not claim to have found the answers to the research questions, but I hope that my findings contribute to building ground for such a discussion in the PD community, where the MACI people remain understudied.

Finally, hereafter I have use the term "MACI people" when referring generally to the user group in co-design. I have used "MACI patient(s)" when I refer to MACI people in relation with healthcare practitioners and I have used "MACI participant(s) when referring to MACI people participating in my workshops.

6.1 Papers Summary

A Participatory Design "Method Story": The Case of Patients Living With Mild Acquired Cognitive Impairments

Çarçani, K. and Holone, H. (2019). A Participatory Design "Method Story": The Case of Patients Living With Mild Acquired Cognitive Impairments, ACHI 2019, The Twelfth International Conference on Advances in Computer-Human Interactions. ISBN 978-1-61208-686-6. pp. 210 - 217

Abstract - This paper presents a story on how patients with mild acquired cognitive impairment(s) (MACI) could be actively involved in Participatory Design (PD) sessions. A detailed description of what mild acquired cognitive impairments entitles is given, followed by an overview of PD and how it might be relevant in the design of new ICT solutions for this user group. The story on how we applied the method is presented as a description and reflection by the authors involved in redesigning the layout of a document in a rehabilitation hospital. The paper aims to attract the attention of PD practitioners to the MACI user group and trigger discussion and questions about PD techniques for patients with MACI.

Keywords: Participatory Design; Mild Acquired Cognitive Impairments; Method stories.

Guidelines for Participatory Design with People Living with Mild Acquired Cognitive Impairments

Çarçani, K., and Holone, H. (2020). Guidelines for Participatory Design with People Living with Mild Acquired Cognitive Impairments. International Journal on Advances in Intelligent Systems. ISSN 1942-2679. 13(1&2), pp. 59- 84

Abstract – Mild Acquired Cognitive Impairment(s) (MACI) are called invisible impairments. This invisibility of symptoms makes that researchers often overlook people with MACI. This is the case in the field of Participatory Design (PD). In this paper, we investigate how to involve people with MACI in designing together digital solutions meant for them. Hence, how to involve people with MACI in Participatory Design. Considering the lack of literature in PD focused on MACI patients, we conducted a borderer investigation of the literature and derived a set of guidelines proposed by PD practitioners for involving people with cognitive impairments in PD. We have collected data on conducting PD with MACI patients from two empirical cases as part of two projects in a rehabilitation hospital in Norway, which offers specialized rehabilitation to people with MACI. We conducted 5 PD workshops with three different workshop outlines. Seventeen people with MACI participated. We present a detailed list of reflections-on-action for each workshop outline. We discuss the reflections with findings from the literature and conclude with a list of guidelines that researchers and designers should consider when involving people with MACI in conducting PD. The paper aims to attract the attention of PD practitioners to the MACI user group with the possibility of expanding the guidelines list in the future.

Keywords - Participatory Design; Mild Acquired Cognitive Impairments; Guidelines.

EquiN: A method to balance power relations in participatory design

Çarçani, K., Bratteteig, T., Holone, H., and Herstad, J., (2021). EquiN: A method to balance power relations in participatory design - Designing cooperative digital solutions for people with cognitive impairments. Journal of Collaborative Computing and Work Practices. (status: under revision)

Abstract - In Participatory Design (PD), the design of a digital solution should involve all stakeholders in co-design. When one stakeholder has a weaker position due to socio-cultural structures, differences in knowledge, or differences in abilities, PD methods should help designers balance the power in the design process, both at the macro and at the micro level. We present a PD method for the healthcare context, which addresses power-relations that arise during the design process and draws on theories about participation and power in the design and organization of change processes. We applied the method in the context of cognitive rehabilitation involving people with Mild Acquired Cognitive Impairments (patients) and their care professionals. We found that providing patients with cue statements supported their creation of choices and hence their "power to" influence the design. The method can contribute to a power "equilibrium" and a positive-sum power relation in PD sessions involving all stakeholders.

Keywords - PD, Power, Method, Healthcare, Cognitive Rehabilitation

6.2 Theoretical Reflections

In order to define practices that can empower MACI people in co-design, I have reflected first on the co-design process and how to organize co-design sessions to support power weak participants. I have drawn my reflections on the work of Bratteteig and Wagner (Bratteteig and Wagner, 2014; Bratteteig et al., 2016; Bratteteig and Wagner, 2016a), which I have presented in Chapter IV. This section includes some repetition from Chapter IV, Section 4.2, but presents my interpretations and reflections on their work and how I have made use of them.

Bratteteig et al. (2016) in the life and death of design ideas, study the lifecycle of design ideas in cooperative design sessions. They found that usually, design ideas start as statements which in Schön and Wiggins (1992) term is an attempt for a move – a move experiment in design. This idea, when not represented in some form, has fewer chances to be pushed forward. When others support the statement initiated by one participant, it becomes a design idea. This idea then becomes a representation when participants get engaged in visualizing it in the design space. The representation can then become part of the design outcome.

Hence, in my interpretation of Bratteteig et al. (2016) study, having a say, influencing the decision-making and the design outcome starts with the ability to come up with statements that have the potential and the opportunity in the design space to move into design ideas. Bratteteig et al. (2016) also refer to Alfred Schutz's work and his theories of the creation of choices in design. They (ibid) argue that influencing the design and having a say in it, is influenced by the ability to seeing, opening, and visualizing different choices.

Thus, MACI people should be facilitated to create choices that will be discussed with the healthcare practitioners who also create choices in the shared co-design space. To motivating MACI people to contribute to the design space by creating choices requires creating an adequate environment for them to engage in the co-design and increase their ability to envision future solutions and be engaged in abstract thinking.

However, creating choices and having a say in the design sessions is not a guarantee that one can influence the decision-making and the design outcome. Bratteteig et al. (2016) discuss how same user group participants amplify the statements of each other. Hence, giving the same user groups the possibility to produce design ideas within the group and join their thoughts and arguments would increase their chances to influence decision-making when involved in co-design with other user groups.

Moreover, Bratteteig et al. (2016) found that those user groups with higher sketching and designing abilities have higher chances of pushing their ideas to the design space and influencing the decision-making and the design outcome. In the case of MACI people and their healthcare practitioners in rehabilitation, the latest may be better in sketching, but this may not always be true because none of the groups are designers or architects. However, the power/knowledge difference between them is the knowledge or awareness of each step of the rehabilitation process (which I describe above as the third suitcase). Another disbalance can come due to the cognitive impairments of the MACI people that do not favor them in visualizing and crafting things. So, to balance power/knowledge in co-designing cooperative artifacts for patient empowerment in rehabilitation, it is relevant to support the MACI people with some form of representation (initial sketching) of the design ideas and with some knowledge or reminder points on the rehabilitation process.

With these theoretical reflections in mind, I describe my findings divided into two parts: focused on how to empower MACI people individually in design and then how to empower them in the cooperative design space with healthcare practitioners. In Figure 6.2, I have visualized how the elements from the theoretical reflection contribute to lifting the MACI patient and creating an equilibrium of power in co-design with healthcare practitioners.

6.3 Increasing MACI people abilities in the co-design space

> *"There is a big transformation in my life, with my.... after sykedom (illness) and there are a lot of things every day now that I can't do, that I did before. And to actually achieve a goal it is very difficult ...if you don't succeed in that day is just a terrible feeling ...because we are all sick."*
> (Redesign project, Patients' workshop 3, Patient 3.2)

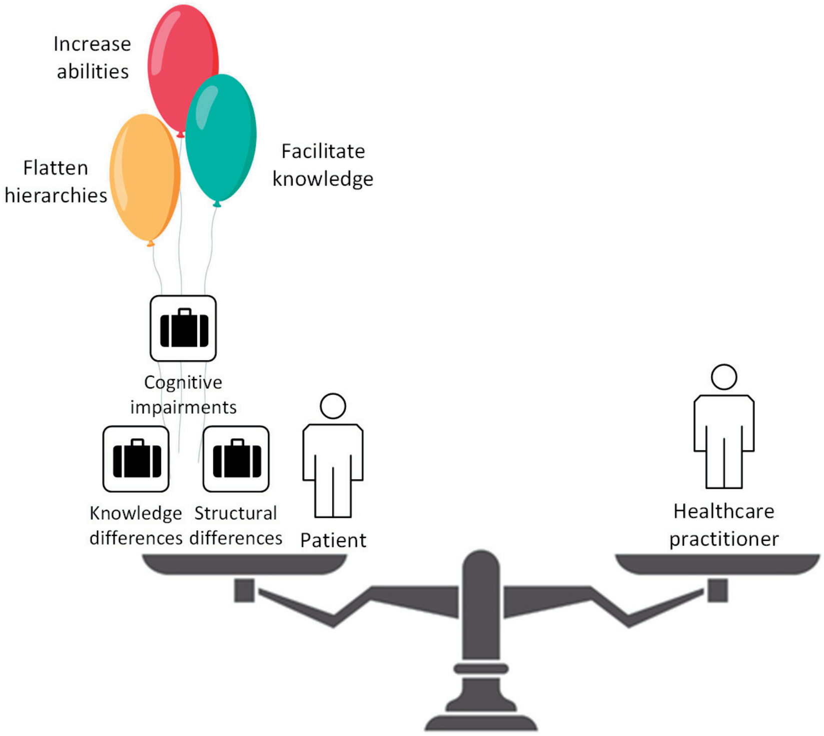


Figure 6.2: Balancing power between the patient and the healthcare practitioners

What the patient is trying to say is that her life has changed drastically from before. She is working toward the goal of recuperating or compensating for her lost ability, but that is challenging and difficult. This quote demonstrates two main characteristics of MACI people that distinguish them from other user groups: they are not born with the disability and do not have a neurodegenerative condition that comprises a deteriorating condition. MACI people have the possibility and hope that through rehabilitation to recuperate or find ways to compensate for the lost ability. Moreover, the impairments are part of a new self and lifestyle they need to get accustomed to.

In Paper III, I have presented some guidelines to consider when involving MACI people in co-design. However, MACI people are very heterogeneous, in the sense that the group varies in terms of condition and abilities. A participant stated:

> *"we are so different, I have had an accident, and the others have had strokes"* (Redesign project, Patients' workshop 2, Patient 2.1)

While the conversation in the workshop continued, the discussion of how different the participants were in terms of needs for rehabilitation and their clinical condition, was repeated many times.

Hence, when considering practices to co-design with MACI people, designers and researchers should consider a high flexibility and adaptability of the techniques and tools applied. While developing new techniques and methods is relevant, I found that sharing "method stories" of empirical work with a group of MACI people served as a good discussion initiator with other academics. "Method story" is a concept used initially by Lee (2014) who suggests that designers should start presenting rich descriptions of as it is – what they actually did with methods in particular circumstances. Hendriks et al. (2015) and Slegers et al. (2016) analyzing the involvement of people with cognitive or sensory impairments in PD, highlights the challenges for coming up with universal methods. Hence, they suggest using the method stories approach to provide rich accounts on how PD researchers apply the methods. Paper IV presents my findings of conducting PD with MACI patients in the form of a method story where I have provided a detailed account of the 3 patients' workshops in the redesign project.

I presented the first draft of Paper IV in a course called Design of Human Technologies and then at the Advanced Computer Human Interaction Conference in 2019 in Athens. The discussions on the paper with other academics in these two venues contribute to providing me with new perspectives for conducting PD with MACI people and empowering them in the process. Hence, the method story resulted useful.

In the next subsection, I describe practices that contribute to empower MACI people in co-design. I have grouped such practices into categories that influence different parts of a co-design session. In each of the subsections, I present several practices that I found empowering in my empirical experimentations of co-design with MACI people

6.3.1 Creating the right environment for a co-design session with MACI people

To make possible a smooth co-design project, good preparation is needed. The co-design process starts way before the co-design session and includes a lot of planning and other administrative things to be taken into consideration. I list below some of the practices for preparing workshops for MACI people.

Learn and cooperate with domain experts in planning and facilitating the PD project

I worked in my study in close collaboration with domain experts - who are healthcare practitioners that are specialized and have experience in working with MACI patients in different aspects of rehabilitation. I cooperated with domain experts in different ways that I describe below. The involvement of healthcare practitioners in co-design is not novel. However, they have been mostly involved as proxies of patients or to support the patients express themselves. In my study, I found that the healthcare practitioners or people who care for MACI people can contribute significantly to other roles, such as planning the PD process for MACI people or co-facilitating the workshops with the designer.

Domain experts planning patients' workshops - I found that the close collaboration with healthcare practitioners in rehabilitation for planning the patients' workshops helped in eliminating possible errors that I, as the designer and researcher, could have done due to my lack of experience with MACI people. To collaborate with domain experts, I organized a trial workshop with the project committee in the redesign project. I applied in the workshop some PD techniques that I was supposed to use with their MACI patients. The initial reaction of some of the domain experts participating was *"we are confused...we don't really understand why are we doing this"*. However, after the first confusion and after I reinstated the workshop's goal, the project committee, compounded by 6 people, appreciated the method and gave feedback on what could work or not with the MACI patients in such a layout. One of the things mentioned was *"patients like telling about themselves, they are used to tell us their stories"*.

They advised me regarding the workshop's length, possible activities that could be overwhelming for the patients, etc. The workshop organized with the domain experts helped in creating mutual learning between us. I continued the collaboration on preparing the workshops even in the digital goal plan project, with one of the domain experts, an Occupational Therapist (OT). Her input was very useful when it comes to the way of communicating with the patients, simple and positive rhetoric, and using different ways to convey the information, either in written format or visually, printed out or digitally.

Domain experts as facilitators in the workshop - I found the involvement of domain experts as facilitators in the workshop helpful both for the MACI patients and for me as the designer. However, having as a facilitator in the workshop a person who is directly their healthcare practitioner can create intimidation for the patients (as part of the structural differences that I highlighted above). Thus, in my workshops, I involved as a second facilitator a healthcare practitioner who had good knowledge of the patient group but was not their direct healthcare practitioner. I have called such a role *"the knowledgeable third party"* in Paper IV.

A knowledgeable third party aims to facilitate the interpretation of the patients' discussions. It provides security to the designer/researcher that a person that is specialized in working with the patient is part of the team. Nevertheless, is not directly influencing the patients' behavior. Instead, for the patients is a safety net that a qualified person that can understand them and their needs at a specific moment is part of the group.

In the redesign project, the knowledge third party was supporting me as the main facilitator during the workshop. Instead, in the digital goal plan project, the knowledgeable third part was a person that had been working closely with me during my research and had become acknowledged with the PD techniques. Thus, she co-facilitated the workshop together with me. The continuous exchanges with the knowledgeable third party, in this case, contributed to creating mutual learning for both. This can showcase the relevance of inter-disciplinary knowledge and collaboration in research when researching specific contexts.

I observed a very good communication of the patient with the knowledgeable third party during the workshop. In some cases, this person resulted helpful in making the patient engage in the conversation. For example, during the second patients' workshop in the redesign project, the patient completed the task, but they were not starting to discuss it in the group. The knowledge third party intervened and said, *"let us go from one field to another. For example, we start with this date here"*. She was referring to the layout of the old document. This specific moment representing a structured way of working, crucial when working with MACI patients, gave the group the first kick-off, and the conversation continued naturally.

Plan ahead to facilitate MACI people understanding of the activities

One of the main recommendations in the literature for working with people with cognitive impairments was **a simple and clear way of communication** with these people during the workshop. To no surprise, this was very relevant for MACI people as well.

> *"In the digital goal plan project, workshop 2, Patient 5.1 and Healthcare practitioner 5.1, happened a lapsus. The figure cues that were provided to them to design the storyboard were from the previous workshop that had in focus another part of the rehabilitation process. When I went to the group to look at their work, I noticed a problem, so I reacted immediately, apologized, and gave them the right pile of figures. When I was apologizing, the patient said to me, "no problem, this is what it is to be a patient in KReSS (the Norwegian acronym for Cognitive Rehabilitation Department (CRD))". I said, "do you mean I need to be part of KReSS(CRD)"..he was laughing and said, "oh no, I meant that things are happening, but no-one knows why."* (Self-Note 1)

In the example above, I found during the workshop's analysis that the design outcome of that vertical group was confusing, and not many relevant ideas were discussed between the patient and the healthcare practitioner. Based on my reflection, the lack of clear communication with the group and the confusion created with the figures influenced the MACI patient involvement in that session of the workshop.

Also, in the redesign project, workshop 2, Patient 2.3 said: *"We need quite clear messages because it becomes very confusing for us"*. The patient was referring to the rehabilitation specialists in the rehabilitation process, but this was also a lesson for the design process.

Another practice highlighted in the literature is to **make the participants to not think of themselves as disabled**. Moreover, in Self-Note 1 above, while apologizing for the confusion, I also added that maybe I should be a Sunnaas patient. In the redesign project, patients' workshops, I also highlighted to the patient that I am "not perfect in Norwegian" so that "could be my disability". The MACI people all come from a life without their current disability. Thus, making them feel good by emphasizing that the challenges are common as well among other people without the ABI can break the ice.

Group size is also relevant to consider when planning the arrangement of the workshops. In all my workshops, I had a maximum of 5 MACI participants in the workshop. The redesign project committee compounded by healthcare practitioner with different specializations in rehabilitation suggested to me that 5 could be a good group size. MACI people usually suffer fatigue and attention problems, so after an hour and a half, one of the MACI participants in the digital goal plan project, workshop 1, said, *"I am very tired now"*. That was also reflected in his involvement in the discussion. Thus, it should be considered to enable everyone to have a say but not to rush the slow tempo of some of the MACI people.

I found that participants had experience and worked well in a group. They were able to build on others' ideas while still keeping their stand if they had a different opinion. An example is from the redesign project, patients' workshop 2 where the participants were all discussing the layout of the goals in the goal plan. Each of them had different opinions, and they said:

> *Patient 2.1 said that he liked the current layout. Patient 2.2 strongly stated that he was different from the others as he had had an accident and not a stroke and wanted to have only physical goals. Patient 2.3 said that the current way was confusing, so maybe he would like to have just goals and not categories for goals. Patient 2.4 also agreed with 2.3 to not have categories of goals as "the categories make sense for them (the healthcare practitioners) not for us" they said.*

However, not all MACI patients have the same abilities. When working in groups, it is the facilitator's responsibility to **give the same time, attention, and possibility to everyone**. I faced a dis-balanced situation in the redesign project, patients' workshop 3. One of the participants was more expressive and eager to tell her opinion. Instead, the other participant was of another typology, more calm and short in her comments. The second facilitator and I ensured that we actively engaged the "quiet" participant in the same balanced time as the more active one. This was also difficult because we did not want to push the participant over her limits as well. I received feedback from healthcare practitioners at the CRD that all the MACI participants in the workshops were satisfied with the workshops' management.

Finally, when working with MACI people, I found that good planning could contribute to the development of a good project. However, inviting the patients to the workshop could not be too in advance in time because MACI people's condition changes from one day to another, so they might feel tired. Being prepared for absences is relevant.

6.3.2 Creating Ideas: Motivate abstract thinking and envisioning future solution

From my empirical study with MACI people, I found that a **task-oriented approach of activities and narrow scoping of a session** can help a MACI person process a line of information at once and to be able to envision more future usage of the solution.

> *In the redesign project, patients' workshop 1, I started the workshop by asking patients regarding their experience with the goal plan and things that they wanted to change. They were told that they could write some ideas in sticky notes set on the table in front of them. I observed that the patients were hesitant about receiving the sticky notes and writing on them. They started discussing the goal plan and each telling for their own experience. While the discussion on this topic went quite well, the participants did not write any sticky notes with their ideas as they were instructed and did not touch the design tools. In the second phase, we asked them to put on paper some ideas for a new goal plan based on the discussion they just had. No-one designed anything. We, facilitators, noticed the hesitation and told them not to stress, and instead of designing, we could keep discussing in the group.* (Self-Note 2)

In order to avoid what in Paper IV I have called "the fear of the blank paper" and also considering the techniques of rehabilitation used in cognitive rehabilitation in which activities are broken into smaller activities, and then the patient learns the activities step by step, I experimented in the other workshops with a more structured task-based format of the workshop. Schön and Wiggins (1992) discuss domains of judgments that the designer uses to see things and make a move. They state that "Because of our limited information processing capacity, we cannot, in advance of making a particular move, consider all the consequences and qualities we may eventually consider relevant to its evaluation." (Schön and Wiggins, 1992, p. 143). In the case of MACI people and their cognition challenges, this is even more serious. They need help to know what they should see. This does not mean limiting the design space for MACI people, only breaking it into minor sequences that are less demanding and help explore the design space in every iteration.

Another thing to consider is to **use activities that are familiar to the MACI people**. For example, relating the activities with a document such as the goal plan that the patients knew and could easily recognize helped them recall familiar memories and discuss them with others.

Moreover, I explored using a future workshop with the MACI people. In Self-Note 2 above is shown how the future workshop did not result successfully on the first try. MACI participants struggled to envision a future solution, a future design for the goal plan. While they were engaged in telling us their experiences with the goal plan and what they were missing to make them more involved, understand, and control the rehabilitation process, they did not suggest future options. Thus, after the reflection-on-action together with the knowledgeable third party, I **" introduced the teaser of future envisioning"**, as an intermediary task in the future workshop. This workshop activity makes the participants think of possible changes in the future by reflecting on the situation as-it-is. I applied such a task in the other four workshops that I organized, and I found that the "teaser of future envisioning" helped the MACI participants generate design ideas and be involved in abstract thinking. All the participants in the redesign project patients' workshops 2 and 3 designed a new version of the goal plan.

Additionally, I found as relevant in helping MACI people to enhance creativity, **the usage of exemplars** which are hand-made designs that demonstrate options of the view of the final version of a design task. I applied exemplars in all my workshops with MACI participants. I have not evaluated the exemplars' influence specifically, but I observed that when used, participants appeared to have more confidence in putting their thoughts on paper. I observed that the exemplars presented in the form of amateur and not finished designs helped the participants relate more to them and feel more confident in designing themselves as they noticed that no finished and polished designs were expected from them. Moreover, I observed that patients and healthcare practitioners used the exemplar as an orientation and then discarded what I had written in it. The reflection note presented next shows my impression for the participants interaction with exemplars.

> *I did not spend time on the exemplars during the workshop in entering in detail on their design. MACI participants didn't do either. They had a quick look, expressed a feeling of relief from what was expected by them, and then continued to be involved in their designs.* (Self-Note 3, Redesign project, patients' workshop 2)

6.3.3 Selecting and evaluating ideas

The practices described above aided ideas generation and contributed to increasing the ability to represent design ideas through sketching. In the three workshops only with MACI people in the redesign project, I did not introduce any activity for selecting and evaluating the design ideas. However, at the end of each of the tasks supposed to be done individually, I included a review session where each patient shared her/his ideas with the rest of the participants. This was done after every activity in a workshop.

While it was not a direct group evaluation, it turned into a such because the MACI participants, as stated above, can bring forward their ideas and stand by those. In the redesign project, patients' workshop 2, while patient 2.3 was presenting his thoughts, patient 2.1 said, *"I had not thought about that... that is a good idea"*. This idea was regarding the usage of healthcare practitioners' photos in the goal plan as an easier way to remember the healthcare practitioners and the activities done with them. As the group review was after each of the stages, the group also had the possibility to build in each step on the ideas shared in the group discussion. In the case of the photo idea presented here, patient 2.1, when making his own sketch of the new goal plan, had integrated the idea of having photos of the healthccare practitioners in his goal plan document design.

Instead, in the digital goal plan project, in both workshops, in the MACI patients' horizontal group phase where MACI patients discussed design ideas together, I introduced a select/evaluate phase that was initially done individually and then as a group. The task given individually was to select out of all the design statements the ones they thought were most important to have in a digital goal plan. They then had to introduce the choices to the rest of the participants by articulating why they had made that choice. Then they had to discuss as a group the choices and come up as a group with five design ideas that they all thought were the most important to have in a digital goal plan. The number 5 used did not have any meaning. I used it as an incentive to discuss the options chosen individually and have to agree on something as a group. This part was missing in the previous three workshops.

I conducted a discourse analysis for each of the five cards that the patients had selected as design ideas in the group (for both workshops), and I found these ways of making decisions and moving a statement to a design idea:

- Grounded move - when an idea was discussed long in the group and all had their own ideas and interpretations of why the functionality was relevant. They shared these ideas and interpretations with one another and unanimously selected the design idea.
- Unanimous move - when an idea was popular. All had similar interpretations on which they agreed upon. They did not discuss these ideas long.
- Modified and joint move - In this category, I listed those design ideas which participants modified to adopt different viewpoints. The other kind of cases were those when participants discussed how to merge two cards that were related to each other.
- An influenced move - This was when selecting a design idea was pushed by one of the participants, who also argued further why that idea was relevant (Paper V presents a more detailed explanation of such a case) and convinced the others.

These different practices of selecting and evaluating design ideas to take further in the next move had different effects when the MACI patients were involved in vertical groups with healthcare practitioners. I have presented examples from each of the above selection strategies in Paper V.

When evaluating the conversations in the vertical groups, I found that the design ideas that had been discussed extensively by the MACI patients in the horizontal group, were the ones that the patient could argue more for the choice. The patient used the previous discussion of the design idea as a strength to influence the decision-making.

Instead, for those design ideas that a MACI participant had not selected on her/his own or discussed extensively upon in the horizontal group, I found that s/he would say: *"I dont know...it was not me who select the card"* (Digital goal plan project, workshop 2, Patients 2.1, 2.2, 2.3)

In conclusion, in the digital goal plan project, I involved MACI people in co-design sessions in generating and affirming (evaluate/select) design moves. I took into consideration the practices of generating design ideas presented in the previous section and tried different techniques for the selection. I evaluated the effect of such practices when studying the MACI people's position in the vertical group sessions. I present more on this later in this chapter.

6.3.4 Other suggestion of practices to co-design with MACI people

When co-designing with MACI people, there are also some other practices that, when applied, can contribute to create the right environment for the MACI people to get engaged in the design, generate design ideas, and be involved in the discussion of such ideas. I elaborate on some of these below.

I found that MACI people, similarly to other groups with similar symptoms, are keener on designing solutions that are interesting, valuable, and have a real purpose. In the digital goal plan project, workshop 2, patient 2.1 told me after the workshop that such workshops are relevant for them to *"express their ideas"*. Moreover, in the same workshop, patient 2.4 and healthcare practitioner 2.4 discussed, *"what is good with this workshop is that you can sit together and discuss things that you agree or not...what is relevant for you"*.

Another element to consider in deciding about PD techniques to apply with MACI people is to provide alternative activities that can support all the participants to engage. I found that it is important to make an appeal to the individual participants' abilities. Moreover, alternative ways to present the tasks are needed. MACI people experience an increase in the time needed to perform activities – the reduced tempo of performing activities. Adapting to MACI people's tempo for doing activities is very relevant for assuring that they do not feel overwhelmed and rushed. This is especially relevant when involving MACI people in co-design with other stakeholders.

I found that adopting as the baseline for a co-design workshop between MACI people and their healthcare practitioner the practices suitable for MACI people, positively influenced their empowerment in co-design. I experienced this in the digital goal plan project workshops. I adapted the environment, length, materials, and tasks to be suitable for the MACI people and applied the same for the healthcare practitioners. In this way, MACI participants felt equal and had the possibility to contribute in their own tempo.

Moreover, the literature emphasizes the need to involve people with cognitive impairments in design in appropriate and familiar environments, which take into consideration the deficits of the participants. This was also the case with my MACI participants. The hospital environment was familiar, and the participants had previously been in the areas where the workshops took place. Moreover, these areas at the hospital are designed to offer easy accessibility for everyone.

Finally, it is relevant to consider activities that are flexible and empathic enough to adapt to the needs of the group. For example, activities that can help create a friendly environment, activities that can boost participants' self-esteem and confidence, and activities that can include an element of playfulness. I experienced that being flexible was required when co-designing with MACI people. Moreover, serving coffee and biscuits during the breaks helped to create a friendly environment. Patient 2.1, in the second workshop of the digital goal plan project, created a video with moments from the workshop and shared that with me to express his enthusiasm.

6.3.5 Practices to influence design results

In the redesign project, I conducted a content analysis of the recordings and the designs, and I concluded in a list of categories representing design requirements that the MACI patients participating the workshops wanted to have in the new goal plan. I presented my coding process and categories to the project committee. We discussed the categories together and reflected on what was feasible in reality and what was not, and concluded on a design requirements list. The project committee's discussion contributed to objectively interpreting patient requirements from different perspectives. An example is the popular idea among participants, in the redesign project patients' workshops, of having healthcare practitioners' pictures in the goal plan document. This requirement was discarded from healthcare practitioners because it was not allowed to include pictures in such a document due to security and privacy reasons. The final requirements were summarised as such:

- Goal, Sub-Goals, Interventions – the three categories should be clearly visualized. Think of a new metaphor for structuring these three hierarchical levels.
- A visual connection between the goal plan and the weekly plans.
- Patient feedback – the document should include a space where the patient can give feedback on how s/he feels about the achievement of the goals. This feedback can be open notes or in a more structured way that healthcare practitioners can use as a measurement mechanism.

I then took these requirements further in the workshop with healthcare practitioners and tasked them to redesign the goal plan as they wish, BUT, they should make sure that the redesign would involve all the MACI patients' requirements. Thus, the healthcare practitioners that are the other users of the cooperative artifacts were the ones to influence the final design. However, the patient voice also was heard and became part of the final result as shown in Figure 6.3. The figure shows how the patients requirements have been included in the new version of the goal plan. The new version was continuously changed

(a) Goal plan page 1

(b) Goal plan page 2

(c) Goal plan page 3

(d) Goal plan page 4

Figure 6.3: New goal plan document

while in use, and today has some more changes from the figure included here. In the first page two main goals are stated. In the second and third page the two main goals are divided in sub-goals. The color of the main goal box is similar to the color of the page where the main goal's sub-goals are listed. Under each sub-goal are listed interventions. In the fist, second and third page for each main goal and sub-goals is included a scale from 0-10 where the patient should declare how s/he feel toward achieving the goal and sub-goals. Page 4 in the figure shows and additional page where the patient can add notes to discuss with healthcare practitioners.

In the digital goal plan project, how the design decisions and the design outcome were influenced happened during the vertical workshops. I present findings on such multidisciplinary group work in the next subsection.

6.4 EquiN: Empowerment of MACI people in co-design with their carer

As empowerment practices on this subsection, I present Equilibria Nudge (EquiN), a method for designing cooperative digital solutions between MACI people and their carers.

> "Equlibria Nudge (EquiN) - a PD method to use in collaborative design of cooperative digital solutions between people with cognition challenges and their carers. "Equilibria" relates to the method aim of achieving an equilibrium of power among the stakeholders through decisions of equilibrating the chances to generate design ideas and to influence the design decision. The method's aim is to serve as a "Nudge" - to alternate the situated discussion during co-design among different stakeholders, instead of imposing rules which will influence the normal flow of the conversation and thus limiting options. Moreover, the method

> is presented as a set of principles that should be taken into consideration in three phases of the method. Tailoring the method to the project in hand is needed." (quoted from Paper V)

The question we ask in Paper V is: *"How to contribute to balance power in PD projects which aim the design of digital solutions that support cooperative work among parts who have an imbalance in power due to the social structure in which they belong or from differences in knowledge level or abilities?* This question have been investigated in the case of co-design between MACI people and their healthcare practitioners.

EquiN method takes into consideration the lifecycle of a design idea (discussed in Chapter IV and also in the theoritical reflections above) and builds on the organizational structure of the so-called "search conference", a method used to discuss changes in the organization by promoting a democratic dialog. Th search conference promotes the discussion for change initially within the group of people in the same unit and then inter-organizationally with other departments or units in the organization (Emery and Purser, 1996).

In EquiN method, to design cooperative artifacts, design ideas should be initially generated among MACI people and among healthcare practitioners. Then, MACI people and their healthcare practitioners will be involved in co-design sessions together. They will have as support in these sessions the design ideas generate in each group. In the co-design space, ideas from MACI people and healthcare practitioners should be discussed and negotiated on how to be represented in the final outcome. The aim of the method is to provide the MACI people with some support in the discussion with healthcare practitioners as a way to balance the power differences in the co-design sessions. The method is conceptualized in three phases:

Start - In the first part of the method, the designer generate design statements (Bratteteig et al., 2016) as possible future design ideas. The design statements produced should touch on different aspects of the current situation and present different possible alternatives. Moreover, the statements should be somehow general so they can trigger discussion in the group and not influence their choices.

One of the suitcases that I listed above as creating an imbalance for the MACI patients in relation to their healthcare practitioners in co-design was the healthcare practitioners' knowledge of the rehabilitation process. MACI patients are going through the rehabilitation process themselves, but they have not yet achieved full awareness or forget some of the activities they have done. Providing some design statements that highlight different parts of the rehabilitation helps them to "see" things that are relevant and be reminded. The aim is that each MACI participant in the workshop visually apprehends the statements and also judges if the statements make sense for her/him. This phase of the method is heavy on the designer/ethnographer/facilitator, who should be very careful in creating the statements and considering the right way to represent them.

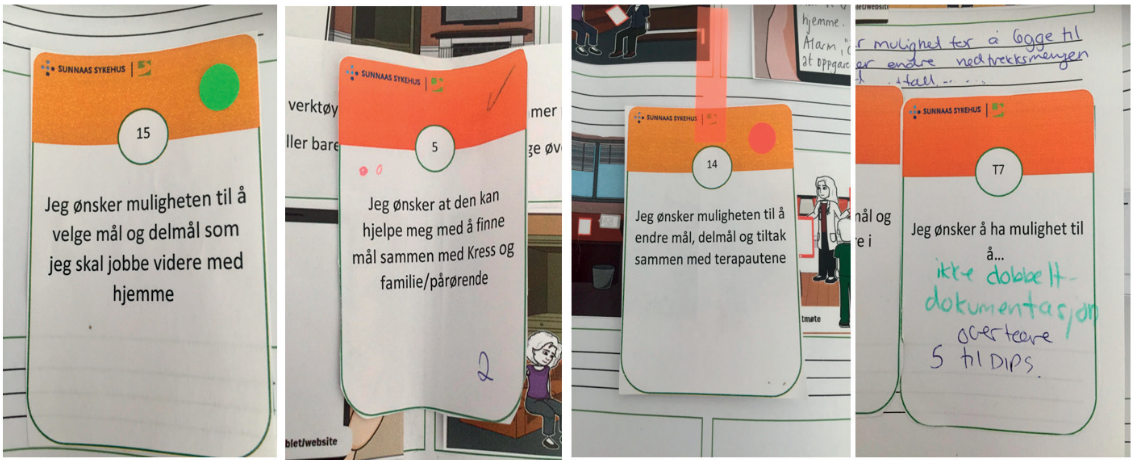


Figure 6.4: EquiN cards

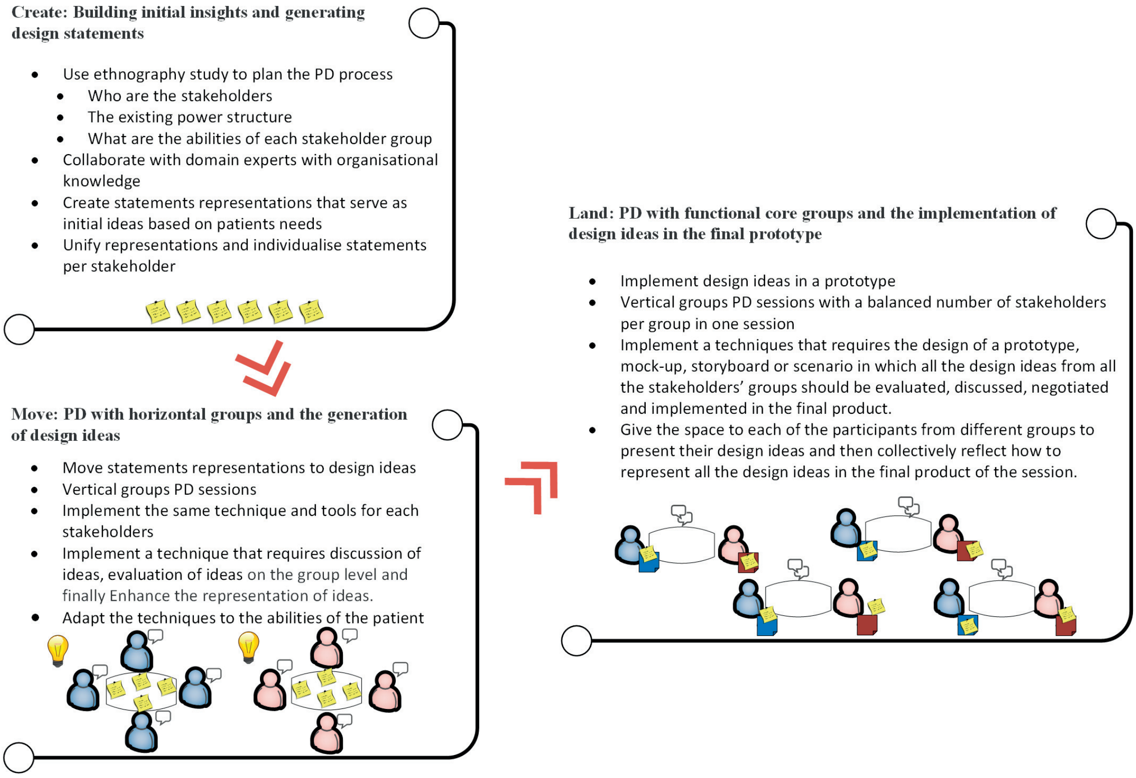
In EquiN method, we recommend using an ethnographic study to learn more about the stakeholders' relations and the current cooperation process. Then use the ethnography knowledge as a resource to plan PD workshops. PD planning should be conducted in close collaboration with domain experts in the field where the new solution will be introduced, who have a deep understanding of the current process. The time that the researcher spends on-site cannot compensate for the knowledge that a domain expert has. However, the PD researcher's ethnographic study supplements the domain expert's knowledge through critical thinking and the commitment to a democratic process.

Bratteteig et al. (2016) also discuss the relevance of representations of the design ideas. In our method, deciding for the representation should be made from the start and by considering the abilities of the weaker user group. The PD researcher should consider the representation of the statements and how the representations can evolve throughout from one PD session to another into new forms of representations a little closer to the final design outcome.

I have applied EquiN method in the digital goal plan project in both workshops. As the representation of statements, I made the EquiN cards, paper-based similar to play cards which included a written statement regarding moments in the rehabilitation process.

Move - consists of organizing PD sessions with horizontal groups (a term borrowed by the search conference referring to people that are part of the same user group of the solution to be designed). The horizontal groups should enable the movement of design statements to design ideas. Hence this part should provide the possibility to participants in each of the horizontal groups to evaluate the EquiN cards, discuss them in the group, interpret them or change them as they wish, and finalize with a set of design ideas that each of the participants in the group supports. The horizontal group should run in parallel. The EquiN cards as representation should be similar for each group. Instead, the cards' statements should be specific to each of the groups resembling their needs from the solution to be designed.

Land - consists of organizing PD sessions with vertical groups (or functional groups - an equal number of representatives from each of the horizontal groups creates a vertical group). In the vertical groups participants should negotiate how to accommodate in their processes and how they cooperate a digital solution that would have all functionalities included in the design ideas brought from the horizontal session (in the form of EquiN cards). They should create a storyboard for the new cooperative processes. To create the storyboard a storyboard template and some animated pictures showing a patient in different moments at the hospital should be provided to help the groups create the storyboard without the need to sketch. There is no intervention in balancing powers among stakeholders in this phase besides the EquiN cards that each participant brings with her/him from the previous horizontal sessions.



Create: Building initial insights and generating design statements

- Use ethnography study to plan the PD process
  - Who are the stakeholders
  - The existing power structure
  - What are the abilities of each stakeholder group
- Collaborate with domain experts with organisational knowledge
- Create statements representations that serve as initial ideas based on patients needs
- Unify representations and individualise statements per stakeholder

Move: PD with horizontal groups and the generation of design ideas

- Move statements representations to design ideas
- Vertical groups PD sessions
- Implement the same technique and tools for each stakeholders
- Implement a technique that requires discussion of ideas, evaluation of ideas on the group level and finally Enhance the representation of ideas.
- Adapt the techniques to the abilities of the patient

Land: PD with functional core groups and the implementation of design ideas in the final prototype

- Implement design ideas in a prototype
- Vertical groups PD sessions with a balanced number of stakeholders per group in one session
- Implement a techniques that requires the design of a prototype, mock-up, storyboard or scenario in which all the design ideas from all the stakeholders' groups should be evaluated, discussed, negotiated and implemented in the final product.
- Give the space to each of the participants from different groups to present their design ideas and then collectively reflect how to represent all the design ideas in the final product of the session.

Figure 6.5: EquiN method

Figure 6.5 represents the three parts of the method and the guidelines for each part. In Paper V I have presented a detailed description and analysis of how I applied the method in practice in the digital goal plan project, workshops 1 and 2. I analyzed the decision-making and the design result that came out of the method. I found that how much a MACI patient had influenced the decision-making in relation to the healthcare practitioner was influenced by the discussion of that design idea within MACI participants in the horizontal session.

Finally, I found that the design result had the patient perspective integrated, and the patient had the possibility to have their voice heard, even though in different degrees depending on the card discussed or depending on the condition of the patient. The EquiN method structure provides a set of practices wrapped in a method that contributes to balance powers in co-designing cooperative artifacts for MACI patients and their carers. Moreover, in Paper V and Chapter V of this thesis, I have explained how I implemented the theoretically inspired EquiN method and how I took in consideration when implementing the method the practices that I listed previously in this chapter. All these contributed to satisfying results of the method implemented.

6.5 Empowering artifacts to be used in co-design sessions with MACI patients

To encourage MACI people to be involved in a workshop in more hands-on activities, I tried different artifacts.

In the redesign project, patients' workshop 1, I used a print-out goal plan document and set that in the middle of the table to encourage discussions. The visual representation of the goal plan worked well for the MACI patients because they could relate to it and start sharing their previous experiences.

> *I observed the same reaction during an interview with a patient regarding the new goal plan's layout. I started by asking questions referring to the goal plan, but the patient was distracted. I then asked her if it was possible to look at her goal plan. When we opened the document, I started asking concretely by pointing fingers at the parts of the document I was referring to. She related better to that and started becoming more engaged and talking about "things she didn't understand in the document", "didnt know about" or "she didn't remember". Using the goal plan as visual stimuli tool was good practice in that moment.* (Self-note 4)

Moreover, from my observations and confirmed by the second facilitator, MACI participants showed more motivation to use **inidvidualized workshop tools**. They seemed to work well in manipulating the tools individually and then share the outcome with others. In the redesign project, patients' workshop 1, I set the tools in the middle of the table and offered to participants to pick up tools such as sticky notes, color pens, and blank paper on their own. I observed that the patient did not use such tools. Instead, in the other five workshops, I provided individual sets of tools to MACI participants. They all worked on the tools and personalized them. In the redesign project, patients' workshop 2, Patient 2.4 said, *"I am using a lot of pink now because my daughters like pink"*. The other three participants accommodate more personal preferences in representing their ideas through the tools provided.

From my practice, I observed that using **low fidelity tools** as part of the workshop toolkit made it easier for the MACI participants to contribute. However, I lack experience with digital toolkits, and further investigation of conducting PD with MACI people building on digital toolkits is needed. Despite my lack of experience with digital toolkits, I would argue that being aware and considering the toolkit's fidelity in a PD project should be a priority. This should be carefully considered with regard to participants' abilities tested through standardized tests.

Finally, I found that **structuring tools** was relevant for motivating participants' contributions to the workshops. This is compatible with the rehabilitation theories for building structure in remembering things and focusing attention and should be considered when presenting PD tools in workshops. Structuring tools means considering the toolkit in parallel with the workshop structure, where each step could have their set of tools that will motivate a MACI participant to express her/himself and influence the decision-making and, consequently, the design outcomes of that specific workshop. In the description of the workshops in Chapter V, I have described how each step in the workshops had specific tools, which were introduced to the participants together with the activities in the workshop. Figure 6.6 shows examples of tools used in two workshops.

Figure 6.6: Examples of workshop materials

EquiN cards

A central part of the EquiN method are the EquiN cards. EquiN cards are cue cards that include some cues for the design of the digital goal plan in a text format.

EquiN cards are a simple representation of some design statements for the digital cooperative artifacts to be designed. The design statements have been formulated based on a previous investigation of the situated action that the cooperative artifact will support and patients' expressed wishes during the first three workshops where the redesign of a paper version of the goal plan was discussed. To define design statements, I initially focused on each activity of the goal planning and goal management process and formulated a set of sentences in the form of wishes of possible characteristics that the digital goal plan could have. Design statements should serve only as the start of a discussion, which can be added, neglected, or rejected later. Opening up the design space is relevant for those user groups which struggle with abstract concepts and envision future solutions. The cards also support structuring thoughts and enhancing design ideas discussion for everyone. However, generating statements is risky because it can influence the outcome. The PD researcher/designer should consider continuously and plan accordingly to avoid such a situation.

The EquiN cards had the role of the nudge, so to enable participants' thoughts and discussions. I adopted a metonymic structure of the sentence. Gibbs (1999), referring to the script theory, states that a metonymic sentence can serve as a script header which, when stated, will recall in people's minds what the script was about. This is very relevant for people with cognitive impairments.

From the evaluation of the two workshops in the digital goal plan project I found that MACI patients had used the EquiN cards in the vertical groups in the following ways:

- Cards as patients' voice - This was the case that the patient had not influenced the decision-making in positioning the cards in the storyboard and had in most cases "agreed with" or "trusted" the healthcare practitioner. In this case the cards were the only patient voice that influenced the design result.
- Cards as patients' discussion partners - In this case, the MACI patient had used the EquiN card as a partner that would help her/him to continue further articulating her/his ideas. In such cases, the decision for where to position the card in the storyboard had been either decided in partnership with the healthcare practitioner or the patient had influenced the decision-making.
- Cards as patients' winning arguments - In this case, the EquiN cards had been used by the patients to influence the decision-making by using the power of the group. In such cases, the patient had stated, *"that was a card that we all agreed upon"* or had used the long discussion regarding the card in the horizontal group to fight for her/his stand with the healthcare practitioner.

A detailed analysis of EquiN cards' influence in decision-making is provided in Paper V. In Paper V, I have found four types of decisions between MACI patients and healthcare practitioners:

- Common decisions (CD) - those decisions in which two participants in the pair discussed a card, expressed their ideas, and together shaped and decided how to implement the card in the storyboard.
- Influenced decision either from patients (ID-P) or care professionals (ID-H) - those decisions which are mainly taken by one of the participants representing patients or healthcare practitioners, but that the other participant had also commented or discussed a little and included some ideas in it.

- One-side decisions either from the patient (SC-P) or the care professional (SC-H) - those decisions in which one part did the major discussion and took a decision where to position the card by asking the other part formal confirmation, accompanied mainly with "yeah" by the counterpart and with no additional argument.

The overall conclusion is that EquiN cards have contributed to bringing some balance of power in co-design between MACI people and their healthcare practitioners (there is a significant number of common or patient influence decisions). They have supported the patients in different ways. However, even in the case that the card was the only patient voice, it still provides a power gestalt together with the patient, contributing a positive-sum power result.

6.6 Conclusion

The finding presented in this chapter aim to contribute to the PD literature of conducting PD with MACI people. I have described individual practices and also a combination of practices in the form of a method. I have also discussed some empowering artifacts as tools to use in co-design with MACI people and some characteristics on introducing the artifacts. This chapter is an overview of what is presented in the papers in more detail. I discuss these findings in relation to the empowerment outcomes in Chapter 8.

CHAPTER 7

PRACTICES OF EMPOWERING PATIENTS IN REHABILITATION

> "The quest for knowledge never ends; it just leads to more curiosities that lead to a greater mind."
>
> *Edmond Mbiaka*

New knowledge emerged also regarding patient empowerment practices in rehabilitation and how to design empowering artifacts for rehabilitation. Hence, in this chapter I walk you through these findings. I have initially presented the papers in which the findings discussed in this part have been introduced. Afterward, I present a conceptual model of work organization in rehabilitation. This is followed by some relevant practices for patient empowerment in rehabilitation. I have compiled these practices in an operationalized model for patient empowerment. I conclude by presenting my findings regarding implications for the design of cooperative artifacts for patient empowerment in rehabilitation.

7.1 Papers summary

Making activities visible: A way to patient empowerment

Çarçani, K., Herstad, J., and Holone, H. (2019). Making activities visible: a way to patient empowerment. In Proceedings of the Halfway to the Future Symposium 2019. pp. 1-7.

Abstract — Patient empowerment is a concept that has found an extensive discussion in health care. It is of significant interest, especially now when the number of people living with chronic diseases has increased. However, there is a stigma associated with being a patient, and contributing to empowerment becomes more challenging. In this paper, we present an empirical study of the cognitive rehabilitation process. We root the case analysis in Computer Supported Cooperative Work (CSCW) research field and further reflect on patient empowerment concept. Through our reflections, we contribute to the discussion of patient empowerment by highlighting some of the work structures that need to be in place in healthcare to make possible patient empowerment. Moreover, we contribute back to CSCW through a situated discourse of concepts in the context of rehabilitation care model. Rendering publicly visible the activities and facilitating the overseeing of events and activities, both in the level of the overall treatment as well as the micro interactions among health care professionals and patients, are found relevant in building awareness among parts and leading to empowerment.

Keywords: Human Centered Computing, Computer Supported Cooperative Work.

Understanding work organization in rehabilitation: A workplace study of cognitive rehabilitation

Çarçani, K., Holone, H., Becker, F., and Herstad, J. (2021) Understanding work organization in rehabilitation: A workplace study of cognitive rehabilitation. (status: under review)

Abstract — In this paper, we present a workplace study of work organization in rehabilitation. The care model in rehabilitation is characterized by the close cooperation of the patient with a multidisciplinary team of healthcare professionals that support the patient through rehabilitation. We examine the practices, procedures, organization of work, and cooperative artifacts used in the case of cognitive rehabilitation in a rehabilitation hospital. The paper provides in-depth empirical observations describing the patient journey during the rehabilitation process at the hospital. We identify and conceptualize four types of work in rehabilitation: collaborative articulation work, self-management educational work, sentimental work, and transition work. Further, we discuss two types of cooperative artifacts: artifacts shared only among healthcare professionals, and artifacts used for coordination between patients and healthcare professionals. We also critically reflect on the organization of the totality of work in rehabilitation by drawing on the illness trajectory framework, and coin recovery pathway as a concept describing the total organization of work in order to achieve a specific recovery goal. We then reflect and describe the rehabilitation process based on the recovery pathways. Further, we discuss the findings in relation to the literature. Finally, we argue that the conceptualization of work in rehabilitation in recovery pathways can support the design of better future CSCW artifacts and improve the design of services in rehabilitation.

Keywords: CSCW, Care, Rehabilitation, Recovery Pathways, Illness trajectory, Care model, Nursing model, Cognitive Rehabilitation, Work, Cooperation, Types of Work.

Designing Personal Health Records for Cognitive Rehabilitation

Çarçani, K., Grisot, M., and Holone, H. (2020). Designing Personal Health Records for Cognitive Rehabilitation, In (ed.), ACHI 2020, The Thirteenth International Conference on Advances in Computer-Human Interactions. International Academy Research and Industry Association (IARIA). ISBN 978-1-61208-761-0. konferanseartikkel. pp. 250 - 259

Abstract — Personal Health Records (PHRs) are digital tools that give people the possibility to have access and control over their health data. They are usually used in situations when the patient is home or in casual encounters between the patient and the healthcare practitioner. Current related literature does not discuss much in terms of PHR usage in hospitals and possible implications for designing such PHRs. In this paper, we present the case of cognitive rehabilitation in a rehabilitation hospital. Patients in rehabilitation should take a leading role in their treatment as a prerequisite for more beneficial rehabilitation. We have analyzed the cognitive rehabilitation case and present a set of six design implications for designing a PHR for the patients in cognitive rehabilitation during their time at the hospital. We discuss these implications from a Computer Supported Cooperative Work (CSCW) perspective, where the PHR has been conceptualized as hybrid information spaces compounded by personal and Common Information Spaces (CIS). We found, that in cognitive rehabilitation, an important element for designing a PHR is its role not only in creating the possibility of sharing information between the patient and the healthcare practitioners, but, at the same time, offering some mechanisms for coordination between them as an incentive of recognizing patients work in the division of labor and helping the patient take more control over his/her rehabilitation.

Keywords: PHR, cognitive rehabilitation, coordination mechanisms, patients empowerment, CIS.

Boundary Objects or Coordination Mechanisms?

Çarçani, K. and Holone, H., "Boundary Objects or Coordination Mechanisms?" (2019). Selected Papers of the IRIS, Issue Nr 9 (2018). 4. https://aisel.aisnet.org/iris2018/4

Abstract — Boundary Objects (BOs) and Coordination Mechanisms (CMs) are terms with a long history in CSCW. They have both been used widely since their initial definition. We find the concepts used in the same settings to describe some form of cooperation among different peoples or group of people. Sometimes it seems that the choice of concepts has not been thought through. Thus, in this paper, we give a detailed description of both concepts, and then we discuss them side by side by highlighting six issues that researchers should take in consideration before defining an object as a coordination mechanism or a boundary object.

Keywords: Boundary Objects, Coordination Mechanisms, CSCW.

7.2 Conceptualizing work organization in rehabilitation

These findings have been presented in more detail in Paper II. They derive from the analysis of non-participant observations notes of practices, procedures, organization of work, and cooperative artifacts used at the Cognitive Rehabilitation Department (CRD) at Sunnaas. The analysis unit was the patient journey at CRD. The aim of the analysis was a conceptual understanding of the organization of cooperative work between a patient and her/his multidisciplinary team throughout the journey.

In Chapter 4, I introduced the conceptualization of work by Strauss (1985) in which he defines a project as an 'arc of work' compounded by a set of tasks that happen simultaneously or in sequence. One example that denotes an arc of work is the concept of illness trajectory. This was coined by Glaser and Strauss (1967) and defined as "the total organization of work done over that course of illness plus the impact of those involved with that work and its organization" (Strauss et al., 1985, p. 8). The authors (ibid) argue that two contingencies influence an illness trajectory for a specific patient: 1) the course of the illness itself and 2) the efforts of the person affected, relatives, and health care practitioners involved to shape the course of illness. Hence, trajectories are uncertain and are influenced by factors that surpass the illness course.

Nevertheless, the work needed and the people involved in an illness trajectory is dependent on the course of illness. Suppose a person suffers from a heart problem, a cardiologist is involved in the arc of work. If the person also starts having kidney problems, then a nephrologist must join the arc of work and cooperate with the cardiologist to define the best treatment for the patient. The treatment itself is focused on improving the heart and kidney function or managing to limit the deterioration of both organs.

I was interested in understanding the work organization in rehabilitation, so I started reflecting on the patient's rehabilitation journey. Findings are presented in the following sub-sections.

7.2.1 Recovery Pathways

I started analyzing patient activities in rehabilitation. In Figure 7.1, I have visualized how the work is organized in rehabilitation for a specific patient (a visualization of the goal plan document). In the black icons, I visualize the activity to be done. Under the activity, I visualize the rehabilitation therapist or therapists that is/are involved with the patient in that activity. In each of the red boxes, I show patient's activities on a specific day that I have considered as the day of reference for the following example.

Activities in the reference day visualised in Figure 7.1: The patient goes for a morning walk with the other patients and the physiotherapist. Afterward, s/he meets with the Occupational Therapist (OT), and the OT fills the mental fatigue scale (MFS) while talking to the patient. Additionally, the OT assigns a task to the patient to read the book "Social life with cognitive changes. Meanwhile, the patient has been tasked to log physical activity that will discuss with the Physical Therapist (PT) by the end of the week. So, keeps a diary for the activities in her/his room and longs the activities when s/he is alone in her/his room. After lunch, the patient reads some pages of the book suggested by the OT. In the afternoon, the patient has a meeting scheduled with the psychologist to discuss memory problems and memory strategies. The last meeting of the day is scheduled to be with the nurse, where they will discuss the patient's family situation and whether or not s/he wants the nurse to get a conversation with her/his kin.

Activities such as the ones described previously make sense in the whole organization of work in rehabilitation when they are seen in relation to patient goals' and sub-goals. For example, the morning walk is part of the patient's interventions to get to know more about her/his physical state and see how much physical activity can withstand. The PT does different activities with the patient under that sub-goal, such as training in the gym, logging physical activities, etc. Thus, the distribution of activities and tasks in rehabilitation is not directly related to the course of illness. These activities, tasks, division of labor are constructed around patient's rehabilitation goals.

A patient that has had a stroke or Traumatic Brain Injury (TBI) has her/his own illness trajectory that starts from the moment the ABI happens. In some studies of stroke patients' illness trajectory, rehabilitation has been defined as only one of the trajectory phases. So, when the patient is in rehabilitation, s/he is already in a part of her/his illness journey. However, in this part, the way work is organized differs from the illness trajectory. The lotus of work is not only the illness, but mostly patient's rehabilitation goals.

In Paper II, we state:

> "Within the illness trajectory of a stroke patient or TBI patient, the organization of work in the rehabilitation phase is not conceptually compatible with the 'illness trajectory" as the organization of work is not influenced by the fluctuations in the clinical conditions but by aims in everyday life.
>
> These differences to the illness trajectory concept led us to a new concept that explains how the work is organized in rehabilitation. Hence, in analogy to 'illness trajectories', we defined a '**recovery**

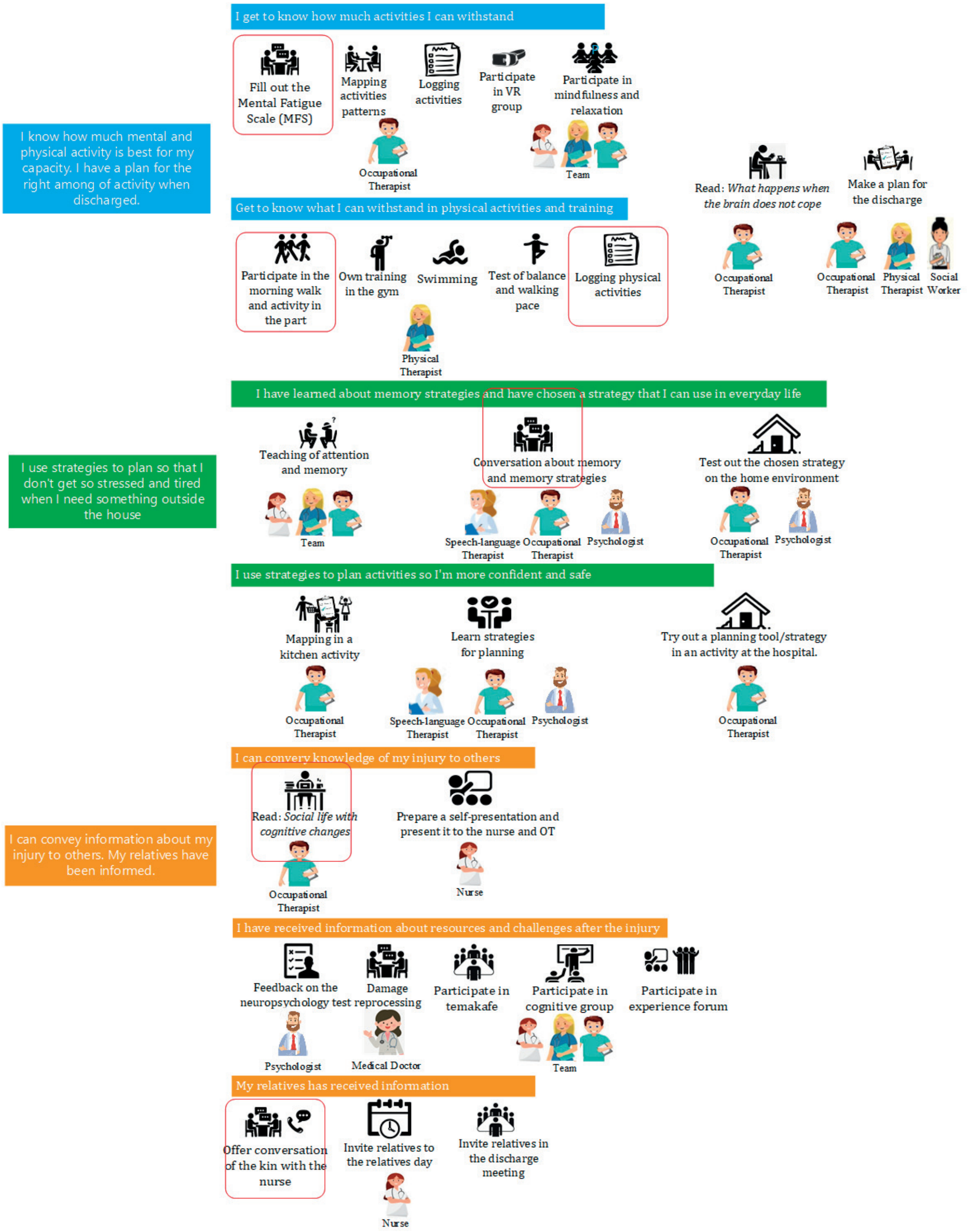


Figure 7.1: Work organisation in rehabilitation based on three main goals on the right, sub-goals on the left and under each sub-goal are listed the respective interventions (in red box are highlighted activities that are done in one of days of rehabilitation at the hospital).

> **pathway′ as the totality of activities, people, and tasks that are bounded through a patient rehabilitation goal**."

In Paper II, we coin the concept of Recovery Pathway (RP). A patient's rehabilitation can have several recovery pathways that can start at once or in different moments during rehabilitation. RPs are related to the patent's rehabilitation goals, and whoever joins and every work task contributing to a rehabilitation goal will be considered part of a recovery pathway. We have explained the concept in the paper as below:

> "′Recovery′ defined by Anthony (1993) and cited in Helsedirektoratet (2018) ′is a deeply personal, unique process of changing one's own attitudes, values, feelings, goals, and skills and/or roles. It is a way of living a life that is satisfying, participatory, and full of hope, even with the limitations that cause suffering. Improvement involves the development of meaning and insight into one's life′. Thus, recovery relates to achieving a stable situation in life, not mandatory recuperation, but also acceptance and adaptability with your new self. Recovery is the process that the survivor undergoes. "Rehabilitation is the process that practitioners use to facilitate recovery" states Farkas (1996). As in our case study rehabilitation is seen as a cooperative process between practitioners and the patient, we have chosen to use "recovery" to emphasize the organization of work driven by the patient and her/his rehabilitation goals.
>
> ′Pathway′ is a concept often used in healthcare, such as clinical pathways, critical pathways, integrated care pathways, etc. In the vocabulary "pathway" is defined as: ′a way of achieving a specified result; a course of action′ (Oxford Dictionary)(LEXICO, 2019). Similarly, in the Cambridge dictionary, it is defined as a series of actions that are taken in a particular situation, especially as part of medical treatment (Cambrige, 2019). In the recovery pathway, we will refer to the pathway as leading somewhere and relating to a human-constructed track of walking, in analogy with patients walking their new pathways."

Recovery pathway as a concept matured after many iterations of content analysis of the data collected in Research Block 2 - the ethnographic study. It is compatible with the goal-setting process model and theories presented in Chapter 2. However, none of the models in rehabilitation literature focuses on the organization of work in rehabilitation based on the sociology of work. I have been inspired for this concept and reflecting on the patient journey by Strauss et al. (1985) and the illness trajectory framework by Corbin and Strauss (1991).

I applied the "recovery pathway" concept to conceptualize the work organization model in rehabilitation.

I found two main phases of work organization in the rehabilitation process: the first part when recovery pathways are planned and the second part when the patient and the multidisciplinary team implement or "walk through" the recovery pathways. I have defined these as "planning recovery pathways" and "situated recovery pathways".

Planning recovery pathways phase involves all the activities and tasks conducted at the hospital that lead to the development of a rehabilitation plan for a patient. This includes activities related to understanding and assessing a patient's condition, defining together with her/him rehabilitation goals, and articulating the division of labor between different actors.

Instead, the situated recovery pathways phase involves all the activities conducted as interventions for the rehabilitation goals and the work to coordinate such interventions. Activities of assessment and evaluation are also included in this part. The assessment contributes to define how a recovery pathway will continue after the hospitalization period and the work that the continuation will imply.

7.2.2 Current patient-healthcare practitioners cooperative artifacts

Routines, procedures, and artifacts facilitate the organization of work at the CRD. Different artifacts contribute to work coordination between the rehabilitation therapists or between the rehabilitation therapists and a patient.

Rehabilitation therapists are mainly supported in their work by the hospital's Electronic Medical Record (EMR) system. In the system is stored any relevant patient record. Each patient has her/his account, and the rehabilitation therapists add journal notes regarding their activities with the patient. This helps the therapists have easy access and an overview of the other therapists' work concerning a patient. Moreover, the therapists have whiteboards where they visualize which therapist is responsible for a specific room's patient or the patients' list in and out of the department in a week.

> *While I was shadowing a physiotherapist in her activities, she told me in the morning that she had three patient meetings in the afternoon. Before going to the meetings, she logged in to the hospital's EMR (she told me that she usually works this way) and scanned through her previous notes for the patient. She also looked at recent notes from other therapists. This helped her have a better overview of the patient's condition, be reminded of previous test results, and prepare for the upcoming session. She wrote down some of the test results as notes to herself... Later that day, when she met the patient, they repeated the balance test. The patient did not remember the previous result. Instead, the physiotherapist had to scroll through her notes that she had retrieved from the EMR previously that day.* (Non-participant observation note)

Another type of artifact that I observed being used at Sunnaas are the ones in use between patients and healthcare practitioners. I observed the usage of two artifacts like this at the hospital: the goal plan document and the weekly plans. The goal plan document is a document that regulated the whole rehabilitation process. The document includes patient goals for rehabilitation, respective interventions, and the therapists who will work in an intervention. The document is generated and stored at the hospital EMR. *"Once the goal planning process in the first week of rehabilitation is finalized with e goal plan meeting, the nurse prints out the goal plan document and gives that to the patient."* (Non-participant observation notes). The patient is supposed to look continuously at the goal plan to make sense of the activities that happen at the hospital.

For the weekly activities, patients are provided with a weekly plan. This is a patient calendar for a week. The weekly plan is generated and stored in a shared folder between the healthcare practitioners. It is printed out and given to the patient when the week starts. The weekly plan activities are related to the interventions and the goals in the goal plan. The weekly plan helps coordinate work between the patient and the therapists and between the therapists concerning a patient. I observed *"the nurse finalizing the weekly plan for next week. She printed them out and prepared them to be distributed to the patients"*. In another case, I observed a *"situation where the patient and the occupational therapists rescheduled a meeting from the morning to the afternoon. The occupational therapist wrote down the change in her notes and changed the document in the shared folder. However, the printed weekly plan for the patient did not change to reflect the rescheduling. The OT had to go later to find the patient to remind him for the meeting"*(Non-participant observation note).

During the workshops, I found that patients did not use much their goal plan even though that was considered the main document for the rehabilitation process.

In the redesign project, patient workshop 2, patient 2.4 said:

> *I would like this goal plan to be something that we can use more actively." I would like the weekly plan and the goal plan to be connected. Some connection that relate to that goal plan.*
>
> *If you find this difficult, what do you think about us....What is your excuse?*
>
> *is too much information, technical and theoretical....*

Instead, in patient workshop 3, Patient 3.2. said:

> *I don't like it when it is so much text. I like more space and other colors. Every time I look at the goal plan, I should read all the goal plan. When I want to do my workout, I want to see it clearly*

It was highlighted many other times in the workshops that the patients were missing a connection between these two documents given to them. This was influencing their understanding of the rehabilitation process and why they were doing activities.

Despite all the confusion regarding the usage of these two documents, I found that patients appreciated using tools in common with the healthcare practitioners in which they could clearly see some of the tasks they had to do. In the digital goal plan project, workshop 1, patient 1.1 said *"I want to be in charge of my goals, I want to have the control and decide...but I also want all the help that I can get for my therapist"*. The same rhetoric was used by almost all the patients that participated in the workshops that I facilitated. The patients wanted to have the possibility to try to share part of the work with healthcare practitioners.

7.3 Practices to operationalize patient empowerment in rehabilitation

Here, I list some practices that I have found to be relevant in contributing to patient empowerment in rehabilitation. Findings have emerged in two ways. One is by analyzing the rehabilitation process observation notes through Computer Supported Cooperative Work (CSCW) lenses and then discussing the findings in relation to empowerment outcomes for patient empowerment. The discussion results have been presented in Paper I in the form of an operationalized model of patient empowerment.

The second way was by analyzing through content analysis the workshop findings. In the workshops, I investigated what patients and healthcare practitioners considered relevant practices to better cooperate with one another to make patients participate, understand, and control their rehabilitation. Therefore, I have analyzed recordings and workshop materials from the three patient workshops, three healthcare practitioner workshops in the redesign project, and two common patient-healthcare practitioner workshops in the digital goal plan project where in focus has been the design and redesign of the cooperative artifacts already in use at the CRD.

Initially, I found that in rehabilitation, the patient and the healthcare practitioners should have a cooperative relationship, and the work involved is compatible with the definition of cooperative work in CSCW. The patient and the multidisciplinary team members are semi-autonomous and interdependent from each other. The inter-dependency stands on the kind of knowledge and the specific perspectives that the patient or the healthcare practitioners bring into the cooperation space (Schmidt, 1990).

Moreover, cooperation between a patient and healthcare practitioners is a central outcome of empowerment. So, studying cooperative work in rehabilitation and how to enhance the cooperation provides relevant information for how to operationalize patient empowerment.

I found the following practices as relevant for patient empowerment in rehabilitation:

7.3.1 Strengthen patient position in the collaborative articulation work

From the analysis of work types in rehabilitation, I found collaborative articulation work as one of the most relevant practices in the rehabilitation process where both patients and healthcare practitioners were involved.

I observed at CRD that during the first week of the patient at the hospital (as I have described in Maria's vignette in Chapter 2), the patient was involved in many meetings with each of the multidisciplinary team members. The meetings involved both assessment and discussion of the patient's condition. Such meetings aimed to locate the patient's position in relation to the clinical condition and function in daily life, and prepare a rehabilitation plan. The rehabilitation plan consists of defining rehabilitation goals, sug-goal, and interventions and deciding how work will be organized for each intervention. This part also involved discussions with the patient and the team on how the interventions would be implemented and who would do what. The division of labor for rehabilitation is established through these meetings.

This process of defining tasks to be done and people involved in each task is compatible with what in Chapter 4, I presented as articulation work, the work of making cooperative work work. Thus, the discussion of rehabilitation goals and possible interventions is the articulation work for patient rehabilitation. From my first meetings with healthcare practitioners, they stated that the patient's cooperation in this phase is very relevant. It contributes to defining rehabilitation goals that are specific and relevant for the patient. Moreover, the healthcare practitioners can help the patient to think and articulate measurable, timely, and achievable goals. Patients also stated that they like to define their own goals and discuss possible options with therapies (as stated by most patients participating in my workshops). Hence, the patient in rehabilitation is involved in the articulation work, and they are considered part of the team and consulted in shaping the rehabilitation plan.

In rehabilitation, articulation work is collaborative as many parties are involved. This is a finding that had been previously argued in the literature (Bagalkot and Sokoler, 2011; Hillgren and Linde, 2006). However, in the case of rehabilitation at CRD, I found that articulation work is collaborative and distributed. The discussion on the division of labor is discussed in separate meetings that each healthcare practitioner has together with the patient. This means that the definition of the treatment comes as a result of many individual distributed meetings between the patient and the healthcare practitioners. Each of the healthcare practitioners evaluates the part of treatment that s/he can support the patient with. In this case, the process is distributed and also collaborative because the healthcare practitioners should collaborate to finalize the treatment even though the discussion of the treatment had happened in distributed meetings.

Both patients and the healthcare practitioners who participated in my study expressed that involvement in defining the treatment and how they will work further in rehabilitation is relevant for them.

In the digital goal plan workshop, workshop 1, where in focus was the discussion of the process of setting goals between patients and healthcare practitioners, both patient-participants stated that they would like to have the possibility to initiate their own goals and then have the healthcare practitioners involved in helping them in shaping the goals better.

In the digital goal plan project, workshop 1, patient 1.2, when asked why do you think it is relevant to initiate your own goals, she said, *"because you can become more aware of your own situation and what one wants to achieve and to have some ownership to the goals"*. The goals in rehabilitation present the treatment.

In the same workshop on the therapist's horizontal group, patients' involvement in discussing the treatment, defining goals, and discussing interventions was brought up. They see the involvement of the patient *"as very relevant for them to understand that they should be responsible for their rehabilitation and this responsibility should start in planning rehabilitation"*.

While the involvement of patients in collaborative articulation work is stated as a relevant practice for patient empowerment in rehabilitation, still the patient position remains at the level of involvement. If you read again patient and healthcare practitioner voices I have quoted previously, it represents what patients and healthcare practitioners think or considered relevant but do not show what actually happens.

> *Something that it has been confusing for me, was on those first days in which has been a lot to talk about and I was a little unsure who and what and which task they would help me and I was stressed if I told the right things to the right person..so structuring that would help* (Digital goal plan, workshop 1, patient 1.1)

This quote from a patient highlights two sides of the same problem. The patient does not understand that it contributes to articulation work, and the healthcare practitioners do not support them in the right things as they are not receiving the right accounts from the patients. So, patient understanding is low, and this influences their participation in the articulation work. Another patient said (Redesign project, patient workshop 2, patient 2.3):

> *We are not filling out this (referring to the goal plan document).. I got this after the goal meeting. I never saw one of this first.*

This shows how the patient forgot everything he did in the first part or that he was not understanding or aware where his goal plan came from and how his talks with the staff contributed. Instead, in the redesign project, workshop 3, patient 3.1 said she was very sick when she came into rehabilitation the first time and could not understand everything regarding the process. She expressed she wished to have had a better understanding from the start.

So, while involvement in articulation work is relevant in patient empowerment, there is a need to improve the understanding of why things are happening. This can contribute to making the patients participate significantly and feel more in control of the situation.

Once the rehabilitation plan is settled, the actors theoretically should know their responsibilities (the patients know less). However, when implementing the interventions for each sub-goal, they need further articulation work on the level of activities for each intervention. For example, I found that in the intervention 'learning strategies to better plan the day' presented in 7.1, both nurse, psychologist, and OT should do therapies with the patient. The psychologists will teach the patient strategies to train and cope with her memory challenges. The OT will help by introducing more coping techniques, such as using the phone to make a plan for the day. Moreover, the nurse will advise the patient on how to schedule relaxation periods when planning the day. The three therapists perform articulation work to define which part of the interventions each of them will be responsible for and when that will happen.

Moreover, I found that articulation work also happens at the level of individual activities among the patient and one of the multidisciplinary team members. For example, between a patient and the OT, the articulation will be on what kind of activities to go through in a session, how many exercises the patient should do, etc. Instead, the patient and the PT in a training session at the gym should articulate how many physical exercises and what exercises the patient will do in the session.

In that case, cooperation in articulation work between the patients and healthcare practitioners should be enhanced at the treatment level and to smaller day-to-day interactions. While patients' involvement in articulation work is a good practice, there is a need to promote participation and understanding so the patient can significantly contribute. This call has been done by all the participants in my workshops who state that *"they want to be in control of their goals"*.

Another aspect of articulation work became relevant in the findings during an interview with representatives from a commune in Norway regarding their management of the rehabilitation process: **articulation work at the level of the care network**. I present, initially, what I mean with care network in rehab.

In 2019, I participated in the European Computer Supported Cooperative Work conference in the workshop called "Who Cares? Exploring the Concept of Care Networks for Designing Healthcare Technologies"[1]. In that workshop, I described the cognitive rehabilitation process and the complex care network of patients in cognitive rehabilitation, referring to care network as defined by Consolvo et al. (2004, p. 24) as "support networks of people who provide the elder with care".

I discussed in the paper that part of a patient's care network in rehabilitation are all the formal and informal stakeholders that support the patient in rehabilitation at a certain moment (reflection from care network from Bratteteig and Wagner (2013)). However, who is part of the care network would variate based on which phase of rehabilitation a patient is in and also in which rehabilitation setting is located in that moment. The care network at the hospital is different from the care network at home and in the local

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[1] https://dl.eusset.eu/handle/20.500.12015/3270

community. Moreover, I argue in the paper that the role of different people varies throughout the rehabilitation journey. For example, the kin may have a smaller role while the patient is at the hospital, but it will have a bigger role when the patient is home.

During an interview with the innovation rehabilitation project manager at Indre Østfold commune, she stated:

> *"How can we organize to support the person's needs? That should be the question".* Further, she added that *"it is important to get away from the linear way of thinking...we can collaborate directly with the hospital, use hospital competence as part of the team...be together in the beginning and then decide what kind of rehabilitation should happen".*

The quote shows that articulation of work and division of labor should not be enclosed within care settings. Articulation work should be at the level of the integrated care network at the beginning of the rehabilitation. The establishment of the care plan by sitting together with the person, kin, specialized hospital representatives, and municipality rehabilitation specialists can divide the work in a way that closes the gaps in services and ensure the highest possible performance. Hence, giving the patients the possibility to be empowered in the process.

7.3.2 Making activities visible and facilitate overseeing them

"I want to know why I am doing this... how is this related to everything else" said one of the patients in the workshops.

The sentence refers to an individual session where the patient meets with one of the rehabilitation therapists. He states his need to have a clear explanation why that session was relevant for his rehabilitation and how that specific session connected to the overall treatment.

One of the EquiN cards selected in workshop 2 of the digital goal plan project by the patients was the one where the patients expressed the wish to have a digital tool that would support their need to gain more knowledge regarding a therapy session. The card said: *"If I have a meeting with a therapist, - I want to know beforehand what we will talk about - I want to have a summary of the meeting - I want to know why this meeting was relevant for me and my goals".* This shows patients request for healthcare practitioners to make their activities more visible for them. Another card selected by the therapists in their horizontal group, which the patients also endorsed, was *"I want to have an alert (notification) showing what is the focus for the session*. This is in the same line as the previous card. Therapists should make visible their aim for the sessions, so the patient can be prepared to participate, understand, and feel control of the situation.

Another example that showed up in the storyboards in the same workshop was the patients' will to "keep track of their activities" and then going in a meeting with their therapists and "visualizing the logs". From both healthcare practitioners and patients, this was seen as an element that could help the cooperation and empowerment by making patient activities visible for the healthcare practitioners.

Another practice that seems relevant based on the storyboards' interpretation is the patients' and healthcare practitioners' interest to oversee each other's activities. The cards: *"to have an overview of my test results", "connect the weekly plan activities with the goal plan"* were among the design ideas in workshop 2 in the digital goal plan project. Instead, in workshop 1, the scenario proposed by both vertical groups (patient-healthcare practitioner) was to give the patient space where s/he can write more about him/herself, and the therapists agreed that they like to read such patient accounts to have a better overview of the patient condition.

Hence, patients are willing to render activities visible to the healthcare practitioners, and the healthcare practitioners want to have the possibility to oversee such activities. Instead, the healthcare practitioners want to make visible the goal-setting process, and the patients are willing to have the opportunity to oversee the process and intervene if and when they are able to. Thus, I concluded that both patients and healthcare practitioners think that making activities visible and facilitating overseeing these activities will contribute to patients' better understanding of their rehabilitation and being able to gain control in the process. Moreover, these two activities contribute to participation and understanding of the process.

In CSCW, rendering activities visible and facilitate overseeing them has been related to the concept of awareness. Both patients and healthcare practitioners are striving to achieve awareness in the rehabilitation process. The patient is a domain expert of her/his own condition, which in rehabilitation is very relevant. Instead, the healthcare practitioners are experts in their domains. When they cooperate with one another in the rehabilitation process, they are both novices in a way. The patient needs to learn about the rehabilitation process. Instead, the healthcare practitioners need to learn on the specifics of the patient because rehabilitation is very individual, and they should adopt suitable therapies for that specific patient. Thus, both need to make activities visible and facilitate overseeing them as a way to contribute to what I call as "transition to awareness."

7.3.3 Establish cooperative artifacts between patients and their carers

As I presented above, there are already in place two cooperative artifacts shared between patients and healthcare practitioners. Both these artifacts play a relevant role in enabling patient involvement in the rehabilitation process and making explicit the patient's activities.

During my observations, I found that both documents currently in use in rehabilitation contribute to facilitating coordination of work with the patient. However, these tools had limited use by the patients, and a lot of coordination work was done "manually" by the healthcare practitioners. *"I have forgotten it in my room,"* said one of the patients (Redesign project, patient workshop

2, patient 2.3), showing that it is difficult to remember to bring this paper document around.

I found that patients are very keen on making more use of their goal plan document. They think that the paper document has a low affordance, and a digital application can better support the goals and interventions, and other functionalities from the planning and implementation of recovery pathways. In the redesign project in both patients and healthcare practitioners workshops, the phrases *"we could have it digitally...we could have an application"* were common.

Introducing artifacts that are shared with the patients gave patients the feeling of ownership in the process. The patients considered the goal plan and the weekly plans as individual tools that contributed to a unique bond with their healthcare practitioners.

In both the redesign project and the digital goal plan project, I studied the design of such cooperative artifacts and how the patients and healthcare practitioners wanted that to be to enhance patient empowerment. In both the planning and the implementation of rehabilitation goals, patients required more alternatives for contributing to the process and to coordinate and communicate with healthcare practitioners. Patients wanted:

> *"to start writing their individual stories that could be shared with the staff, have the possibility to initiate their goals and then check it with family and healthcare practitioners, have the possibility to received all the results of tests in a folder, received summaries of the meetings and information about interventions in the digital tool".* (A summary of design ideas selected in the digital goal plan project)

On the other side, healthcare practitioners discussed that they *"could be willing to read patient feedback, to work on the goals initiated by the patients, to write upfront the scope of meetings and create summaries for the patient"* (A summary of design ideas selected in the digital goal plan project). The vertical groups' discussion confirmed the previous findings that both artifacts were appreciated by the patients and considered as empowering artifacts. However, these artifacts needed to offer more flexibility to parts and enable further collaboration between them.

In Chapter 6, I presented a situation with a patient (Note 2) where he said, *"things are happening at CRD, but no-one knows why"*. The shared artifacts that enable cooperation and coordination can contribute in this direction. In another vertical group in the digital goal plan project, workshop 2, patient P2.4 and healthcare practitioner T2.4 discussed that such a tool would be very relevant as support during rehabilitation to share things with each other and report for activities done.

In CSCW, different cooperative artifacts have been defined (as I listed in Chapter 4). I discuss the design of such a cooperative artifact for rehabilitation more in detail below, where I present my findings for characteristics of empowering artifacts in rehabilitation. Analyzing the storyboards in the two workshops in the digital goal plan project, I found that both patients and healthcare practitioners wanted such artifacts to include a coordination flow that would make explicit the tasks each had to do. This, was always followed by a discussion on flexibility to adapt to the patient's ability. However, it seemed relevant that the patient had tasks clearly stated in the cooperative artifact.

In Paper V, I have discussed the necessity to conceptualize a Personal Health Record (PHR) in rehabilitation at the hospital as a coordination mechanism as defined in CSCW. Coordination mechanisms are artifacts that represent an imprinted protocol of processes or procedures which help to coordinate activities between semi-autonomous agents. The patient and the multidisciplinary team that works with the patient at the hospital are semi-autonomous agents because they depend on each other to make possible the planning and implementation of the rehabilitation plan.

Moreover, a coordination mechanism serves as the incentive for changing the status of an activity happening in a cooperative work setting, thus, triggering other activities for other actors. These characteristics of the coordination mechanisms to assign parts of the tasks to different actors will help make visible the patient work and role in the process and highlight the work that each of the multidisciplinary team does during the rehabilitation period.

Finally, opening the cooperation space and introducing cooperative artifacts to be shared between a patient and her/his healthcare practitioners is a good practice for patient empowerment in rehabilitation. These cooperative artifacts become incentives for a patient to participate, understand, and control the rehabilitation if they function as coordination mechanisms where the patient's and healthcare practitioners' tasks are made explicit.

7.3.4 Consider all patients' Common Information Spaces (CISs)

In this thesis, I present a study that focuses on the empowerment of a single patient in relation to her/his care network at CRD. Patient empowerment also constitutes of the empowerment of the patient also in other cooperative spaces, such as the patient in relation to other patients with the same condition, or the patient with carers at home, etc. An example are the group activities/therapies at the CRD. One of those cases is what is called a morning meeting. I participated in such a meeting, and I wrote the following note showing how the patients share things with each other that help their rehabilitation:

> *Next it was the morning meeting with the patients – One of the nurses was the one running the meeting. When we entered the room, the patients were socializing with each other. One of the patients told about her story and the challenges after the injury. Even though her situation was not the best, she was using a phone and played her favorite music*. (Non-participant observations)

Patients have also other group activities/therapies at the CRD, such as the Experience Forum, VR groups, Mindfulness, Tema Kafe etc. Group therapies are considered very helpful for patient rehabilitation.

Such patient groups where the patients share common information resembles what in CSCW are defined as Common Information Space. I have already presented in Chapter 4 that a CIS is a concept that has been discussed extensively in CSCW. It is a concept that characterized cooperative work settings. Conceptualizing patient relations to others in healthcare as CIS can contribute to opening up new discussion of what is possible to be put in the common information space and what not and what can the common information enable in terms of cooperation and labor division between actors.

CIS has been discussed a lot (Zhang et al., 2017; Scupelli et al., 2010; Bossen, 2002; Bannon and Bødker, 1997) in regards to work coordination between healthcare practitioners in different hospital parts. However, there is a lack of discussion of CIS between patients and healthcare practitioners or between patients.

In the digital goal plan workshops, considering all CISs that the patient is situated through rehabilitation was discussed as an element that can support patient empowerment. An EquiN card selected by healthcare practitioners was the one stating,*"I would like to have help to coordinate with others in the local communities on how the patient will continue rehabilitation home"*. This shows that there is a CIS that the patient shares with healthcare practitioners at the hospital and another CIS the patient shares with local rehabilitation therapists. The card shows the wish of healthcare practitioners to have a facilitated share of information between the CISs. When discussing how to implement this design idea in the rehabilitation process and present that in the storyboard, 4 out of 5 vertical groups discussed that that the healthcare practitioners should coordinate the sharing of information between CISs. In only one vertical group, the result was different. The healthcare practitioner stated:

> *HP: This is an activity I can do.*
> *Patient: I think we can share. I know who I want to share the document with, and we can both reflect and discuss how to facilitate each other's work.*

The patient brings a new perspective to the way the two CISs share information. He puts at the center himself, as the hub of such coordination. This perspective is relevant in increasing patient's understanding and participation in the decision-making regarding the treatment and the share of her/his own information.

Above, I discussed the collaborative articulation at the level of the care network. Such articulation work can help in making possible the integration of the CISs that the patient becomes part of during her/his rehabilitation journey. However, what that patient above brings to the attention of empowering practices is that the patient should sit in the middle of these CISs that are interrelated through her/his need for care.

7.3.5 Facilitating different kinds of negotiations

Another relevant element to consider in an operationalized model of patient empowerment is what Palumbo (2017, p. 32) highlights in the dark side of patient empowerment: "what can be actually implemented and how the cooperation should happen". Facilitating negotiation practices is a relevant aspect for supporting empowerment. However, different types of negotiations should be considered.

First, I found in rehabilitation that the negotiation of the coordination of work at any time during the process is an element that can make the patient willing to take more control of her/his rehabilitation process.

The negotiation of coordination is a very relevant element of patient empowerment because it provides everyone the opportunity to be involved in the cooperation space as much as they can and not feel pressured or left alone. So, the patient would be aware that s/he has a task assigned but can negotiate to skip or get support from healthcare practitioners if needed.

I am bringing again to your attention what patient 1.2, digital goal plan project, workshop 1 said: *" I want all the help I can get"*. This was stated after he had strongly argued how he wants to write his own goals, take the initiative in the process, and so on. Moreover, he picked on something else that is relevant to the necessity of negotiation. He said: *"I want to define my goals or chose from a goals database, but I am sure that this is not the same for all of us. So, I think that each should find his way"*. The patient means that somehow should be a possibility that patient's cooperation with the healthcare practitioners fits the patient's condition. Not always the patient would be able to take charge of activities, and in such cases, the patient should know that healthcare practitioners will support.

Second, the necessity to negotiate is not only on how the work is coordinated but also on what the work is about, its content. One of the EquiN cards in the digital goal plan project, workshop 2, that was similar for both patients and healthcare practitioners, was *"having the possibility to re-negotiate and change goals during rehabilitation"*. For the patients, this required an adaptation to their needs. For the healthcare practitioners, these involved changes in the arc of work and additional activities to do. In the workshop, all the groups agreed that having the possibilities to change goals was relevant. However, healthcare practitioners were more skeptical as they knew that that would mean changes in routines and procedures.

I will describe in the following note a situation that I encountered during the redesign process which shows how relevant it is to have the possibility to negotiate needs and take into consideration both patients and healthcare practitioners views. The empowerment of patients, making them involved, understanding, and in control should be done by negotiating a middle way with healthcare practitioners.

> *"I also observed the necessity for negotiation during the testing phase of the new goal plan document layout. In the patient workshops, we found*

> *that patients wanted to have a way in the document to provide feedback on how they felt regarding their progress in rehabilitation. One of the ways proposed was to have a scale from 0-10 where they could report where they felt they stood toward achieving a specific goal or sub-goal. I included such a thing in the design of the new goal plan document. The change in design was also associated with changes in work processes. So, it was decided that one of the staff members would have a meeting with the patient and ask her/him to score the sub-goals. This was scheduled to be at the end of each week. This scoring would be used as a measurement of how the patient felt was advancing in her/his rehabilitation and, if needed, make changes to the rehabilitation plan.*
>
> *After a couple of months of trying out this new routine, I was reported back that it had become overwhelming for the staff to keep up with the scoring every week. That had caused some of them to be sloppy on continuing the procedure or even giving it the right time, attention, and relevance in the encounters with the patients. They already had a high workload in the department. So, trying to support patient needs had created problems for healthcare practitioners, who normally, during the process, had been enthusiasts in finding new ways to empower patients. Thus, together with CRD management they had agreed that the scoring would happen every second week.*
>
> *This was revised again. Finally, it was decided to do scoring after establishing the goal plan, in the middle of the stay, and before discharge."*
> (Log Notes, Redesign project)

7.3.6 Include transition work and self-management educational work

When analyzing the types of work in cognitive rehabilitation (presented in Paper II) I found that one relevant type of work that has a strong contribution to patient empowerment is the one that I have defined as "transition work" - the work put in place from the medical staff at the hospital and the patient to make possible the smooth transition of patients from one healthcare setting to another, so the patient continues the intervention plan even in his/her local community.

This work is present in rehabilitation in three different activities: One cluster of activities in the transition work relates to the work of giving rehabilitation exercises for the patient to perform at home while s/he is still in her/his hospitalization period. It also includes the work and effort that the patient puts into these activities. One example is logging activities during a normal day in patient life. The patient does the activity during the weekend and discusses that in the following week with the therapist.

Another cluster of activities in the transition work is the set of activities that happen at the hospital, aimed at everyday life after rehabilitation. For example, activities like maintaining a weekly plan or learning how to tell others about their situation and trying the presentation in front of the nurse and OT. The following quote extracted from observations' notes shows an example of this kind of transition work interventions:

> *"the patient was assigned to create a weekly plan for the first week home after the discharge. After the patient was finished, she looked at the plan together with the OT. The OT asked the patient if she would feel tired if she had many activities on a Monday. After thinking about it, the patient stated that it would most probably happen that she would feel tired. So, the OT suggested including at least a 30 minutes break between demanding activities. In the weekly plan, "having a rest" is presented with the light blue color, so the OT suggested using more light blue colors in the plan."*

The two types of transition work that are common in rehabilitation represent a practice that can strongly contribute to patient empowerment.

In the digital goal plan project, workshop 2, one of the most discussed topics was the patient preparation for going home and continuing the rehabilitation in the local community and at home. In all the storyboards it is included the EquiN card that represents the design idea that patients want to start negotiating the transition to home since they are at the hospital. The card states, *"I want to have the possibility to chose goals and sub-goals that I can use at home*. This card in all the storyboards is positioned in the middle row, where are listed activities that the patient and healthcare practitioners should do together.

Based on patient insight from the workshops, I found that patients considered such transition work practices very helpful. In one case I observed at the hospital, two members of CRD went to visit the home of the patient to consider the conditions and prepare a better plan for her. The aim was to get maybe a better overview of the patient's needs. One of the patients that I interviewed stated, *"I like receiving an assignment for home. I can discuss them with my wife and we can both understand and learn different techniques. She wants to be involved, and she can help me better this way."*

Another kind of work that I have found from the analysis of my observation data is what I define in Paper II as "self-management educational work" – referring to the work that staff and patients do to build a patient's health literacy and self-management skills.

The involvement of the patient right from the beginning of the rehabilitation process to enable reflection on their individual goals and the explicit relation of the interventions with the patient goals is part of the self-management educational work. The aim of the rehabilitation per se is not confined to the walls of a specialist hospital. In one of my meetings with an OT, she emphasized how "the involvement of the patient and the self-management of her/his situation is essential for guaranteeing a successful recovery".

The self-management educational work involves a) learning new strategies to manage the new situation and b) internalize these new strategies learned and use them to cope with everyday life once the rehabilitation is finished.

Some of the activities under this type of work in cognitive rehabilitation are learning strategies to plan your day, learning strategies to remember, learning how to tell about your injury, learn how to manage the rehabilitation.

This type of work constitutes a big part of the rehabilitation, as the final aim of the patient is to manage her/his situation in the best way possible with as little support as possible. It does not aim specifically at patient empowerment, but it can have an effect on it. First, such a procedure is desirable by patients who have as the scope of rehabilitation learning techniques that can make them feel ownership of the rehabilitation process. On the other side, this type of work puts a demand on the planning of the recovery pathways of rehabilitation and how to enable the understanding of what is going on in that period. In the digital goal plan project, workshop 1, both patients expressed willingness to start the goal reflection process before coming to the hospital, showing that this could be a way for them to reflect on themselves and the goals and feel more in control.

In Paper II, we argue:

> "Self-management educational work," ... requires the involvement of both the patient and the therapists. Thus, it should not be considered only as patient work. What makes this type of work different from other types of self-care work is that it emphasizes the cooperation between the patient and the healthcare practitioner. In the above example, the patient is introduced to the handy calendar by the OT. The patient seems to like the tool but proposes a different way to use it that will fit his needs. The OT, on the other side, helps the patient to configure the app to his needs. Self-management educational work with an emphasis on the cooperation of patient-healthcare practitioners may include different types of work described in the literature only as healthcare practitioners work presented in Strauss et al. (1985) such as information work, data work, bodywork, monitoring work, medication work, restoration work, machine work etc. (Paper II, p. 21)

An operationalized patient empowerment model

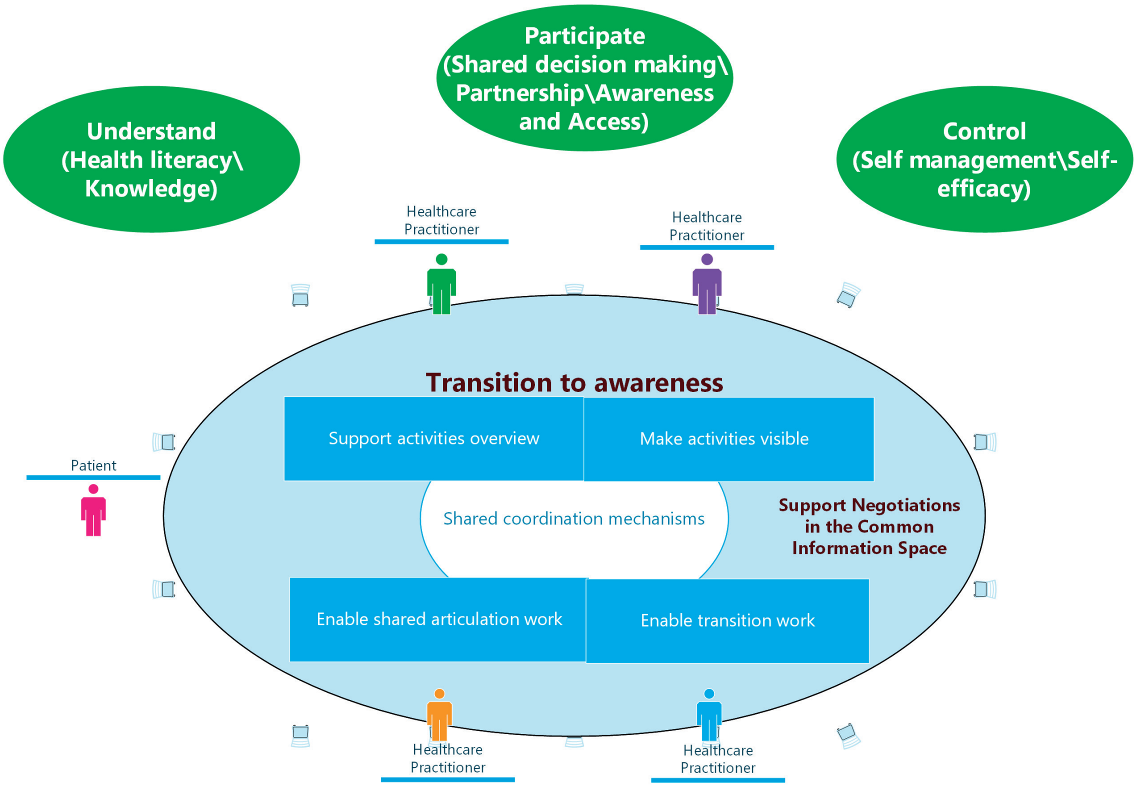


Figure 7.2: Revised from Çarçani et al. (2019): An operationalized model of patient empowerment in rehabilitation

Based on the practices presented above, I have updated the model of operationalizing patient empowerment that I have presented in Paper I, and I present an updated model in Figure 7.2. The figure is just a visualization of the practices presented above. The aim is to show that in patient empowerment is relevant to highlight the needs of both patients and healthcare practitioners (as shown seated in the round table). They share a common information space in which some practices should be established as building blocks toward empowerment outcomes. These are:

- patient participation in articulation work,
- making activities visible and support overseeing them - defined as “transition to awareness” ,
- introducing coordination mechanisms to be shared between patients and healthcare practitioner
- support different types of negotiation
- consider all patients common information spaces
- support transition work and self-management educational work

7.4 Implications for designing cooperative artifacts for patient empowerment in rehabilitation

In this section, I answer sub-research question 2.2. The findings and discussion regarding this question are partially presented in Papers I, II, and more specifically in VI. There are also some accounts of findings and discussion relevant for this question in Paper V when evaluating the method and presenting examples from the workshops' findings. Moreover, Paper VII's findings are used in this section to discuss implications for design for a technology that facilitates cooperation between a patient and her/his healthcare practitioners throughout the whole rehabilitation journey and is not tied to one ward or setting.

My position regarding technology in rehabilitation

I want to initially clarify my position regarding my view on the role of technology in patient empowerment in healthcare. I have considered cooperative artifacts as relevant empowering artifacts for supporting empowering practices and empowerment outcomes in rehabilitation.

I started my study quite open in reflecting and discussing patients' and healthcare practitioners' needs for cooperative artifacts and empowering practices. The discussion on technology, especially Information Communication Technology (ICT) surfaced in the workshops with the patients and healthcare practitioners. Moreover, as I have argued in Chapter 3, I see cooperative artifacts and cooperative computational artifacts as supporting empowering practices in rehabilitation.

Hence, in analogy with my paradigm, I have a social constructivist view on technology and its role in patient empowerment in rehabilitation.

7.4.1 Implications for facilitating the empowering practices

Initially, part of the design implications for an empowering artifact are related to supporting the empowering practices listed above, such as:

- The first thing is to include in the empowering artifact mechanisms that encourage the involvement of the patient in articulation work. In the digital goal plan project, workshop 1, patients and healthcare practitioners in vertical groups proposed these functionalities:

  > *The patient is introduced with the application at the outpatient clinic. Once logged in the application, the patient can access a page where s/he can select the goals from a goals database. After the selection, the patient can customize the goals. Also, the application has a section where the patient can initiate writing her/his story and things that he wants to show with therapists. The healthcare practitioners have their own mobile or web app where they can log in and have access to what the patient has been writing. The healthcare practitioners can*

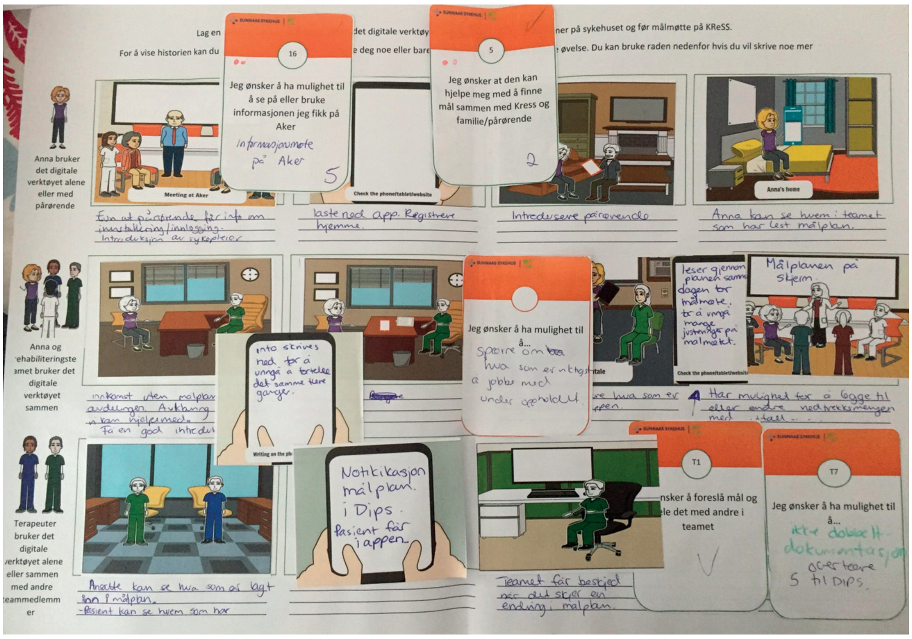
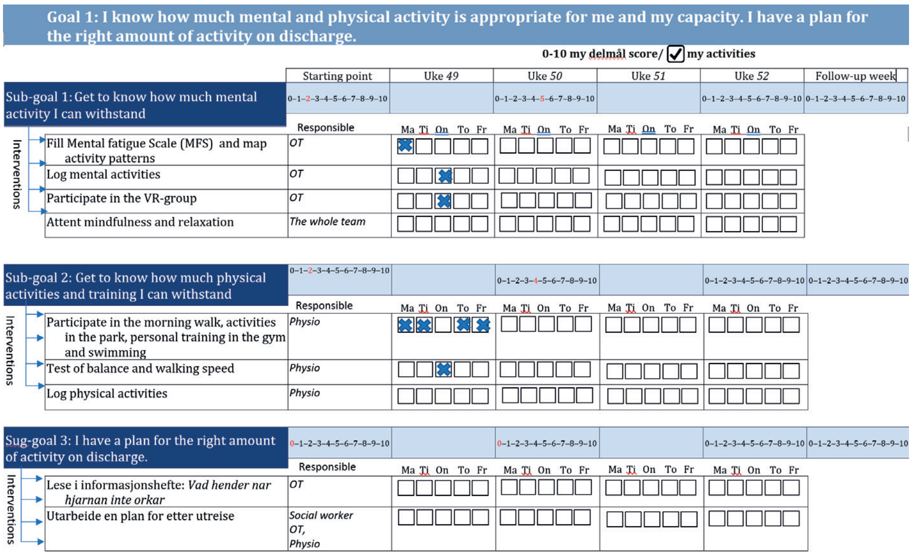


Figure 7.3: The digital goal plan project, workshop 1, storyboard 1.1

> *add additional questions for the patients. When the patient comes to the hospital, they can discuss together, review goals, discuss possible interventions and draft a final version of the goal plan. The patient would have all the time access to the goal plan and make adjustments. The same for the healthcare practitioners. Both parts would have to confirm the last version. The scenario described here is shown in Figure 7.3.*

- An empowering artifact should create the possibility to negotiate the cooperation which could be adapted to individual needs. In the scenario presented above, if the patient finds it difficult to initiate the goals, the healthcare practitioners can suggest to the patient to focus on writing her/his story, and when the patient goes to the hospital, they can together in a session, start thinking and drafting goals. One other example is negotiating and changing the schedule times for interventions. This is possible by sharing the patient calendar. If the patient feels tired to attend a meeting, s/he can send a request to the therapist for a new time. The therapists can then look at the patient's calendar and propose a change base also on her/his availability.

- The empowering artifact should facilitate making activities visible both from patient and healthcare practitioners and facilitate them to oversee the other's activities. The main functionality regarding such practice is to connect the patient calendar activities with the patient's goals. This was the main requirement both from patients and healthcare practitioners in all the workshops. In order to make possible such visibility and overseeing of activities in the redesign of the new goal plan document, I added a calendar as shown in Figure 7.4. In the document are represented



Goal 1: I know how much mental and physical activity is appropriate for me and my capacity. I have a plan for the right amount of activity on discharge.

0-10 my delmål score/ ☑ my activities

	Starting point	Uke 49	Uke 50	Uke 51	Uke 52	Follow-up week
Sub-goal 1: Get to know how much mental activity I can withstand	0–1–2–3–4–5–6–7–8–9–10		0–1–2–3–4–5–6–7–8–9–10		0–1–2–3–4–5–6–7–8–9–10	0–1–2–3–4–5–6–7–8–9–10

Interventions	Responsible	Ma Ti On To Fr	Ma Ti On To Fr	Ma Ti On To Fr	Ma Ti On To Fr
Fill Mental fatigue Scale (MFS) and map activity patterns	OT	☒☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐
Log mental activities	OT	☐☐☒☐☐	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐
Participate in the VR-group	OT	☐☐☒☐☐	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐
Attent mindfulness and relaxation	The whole team	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐

	Starting point	Uke 49	Uke 50	Uke 51	Uke 52	Follow-up week
Sub-goal 2: Get to know how much physical activities and training I can withstand	0–1–2–3–4–5–6–7–8–9–10		0–1–2–3–4–5–6–7–8–9–10		0–1–2–3–4–5–6–7–8–9–10	0–1–2–3–4–5–6–7–8–9–10

Interventions	Responsible	Ma Ti On To Fr	Ma Ti On To Fr	Ma Ti On To Fr	Ma Ti On To Fr
Participate in the morning walk, activities in the park, personal training in the gym and swimming	Physio	☒☒☐☒☒	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐
Test of balance and walking speed	Physio	☐☐☒☐☐	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐
Log physical activities	Physio	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐

	Starting point	Uke 49	Uke 50	Uke 51	Uke 52	Follow-up week
Sug-goal 3: I have a plan for the right amount of activity on discharge.	0–1–2–3–4–5–6–7–8–9–10		0–1–2–3–4–5–6–7–8–9–10		0–1–2–3–4–5–6–7–8–9–10	0–1–2–3–4–5–6–7–8–9–10

Interventions	Responsible	Ma Ti On To Fr	Ma Ti On To Fr	Ma Ti On To Fr	Ma Ti On To Fr
Lese i informasjonshefte: *Vad hender nar hjarnan inte orkar*	OT	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐
Utarbeide en plan for etter utreise	Social worker OT, Physio	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐	☐☐☐☐☐

Figure 7.4: Improving the goal plan to support the patients understanding of the activities done at the hospital in relation to her/his own goal

all the days the patient is at the hospital (grouped per week number). The aim behind such a design was that in every individual session, the patient and the healthcare practitioners would start the sessions by looking at the goal plan. The healthcare practitioners would tell the patient which interventions they would work on that day and set a cross on them on the document. So if it is Monday, week 49 and the OT meets with the patient to fill the Mental Fatigues Scale, they would set a cross in that box as shown in the figure. Moreover, if the patient would go on a morning walk, once returned, s/he would cross that activity in the interventions list under sub-goal 2. In the figure, the patient seems to have skipped the morning walk on Wednesday. Hence, the new document layout would make it visible for the patient to see if s/he had worked with any of the interventions contributing to a specific sub-goal. Instead, for healthcare practitioners to see if the patient had skipped any activity.

Further, this would help evaluate sub-goals and state how much from 0-10 the patient felt that s/he was achieving that sub-goal. If the patient had not worked in a certain week with interventions for specific sub-goals, there was no expectation that the patient would score better than last week. If the patient had had interventions for a sub-goal but still not feeling any advancement, the multidisciplinary team had to evaluate the situation and consider changes.

Another functionality that I highlighted above was the interaction of a patient and a healthcare practitioner in a session. The patient should share comments and opinions with the staff and how they found the session. Instead, the healthcare practitioners should add the session's

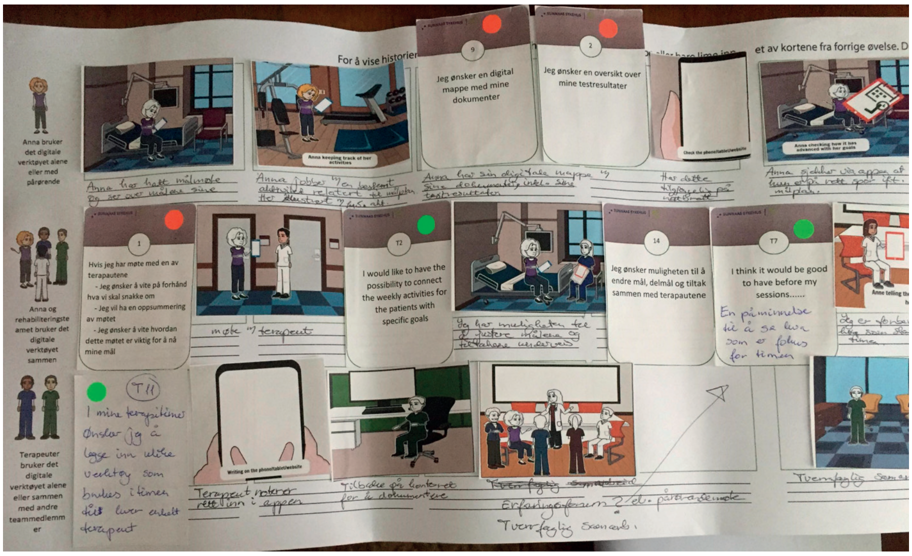


Figure 7.5: The storyboard created by vertical group 2.2 in the digital goal plan project, workshop 2.

connection with the goals and a summary or description of the session in the cooperative artifact. In this case, the cooperative artifact would facilitate healthcare practitioners to make their activities visible. However, the patient should have access to such healthcare practitioner notes, and the healthcare practitioner should have the possibility to look at the patient impressions from the sessions. Hence, they also can oversee the activities of one another.

- Support transition work – In this case, the empowering artifact should facilitate keeping records of tests, keeping records of materials, books, applications learned at the hospital, record of sessions etc. Such records would allow the patient to remember such activities once home and, if wanted, share them with local rehabilitation therapists and avoid double work. Figure 7.5, (in Norwegian) visualizes the patient and healthcare practitioners' willingness to be involved and contribute in transition work to better prepare for the time home.
- Support self-management educational work – The empowering artifact should provide the opportunity to the patient to continue using the goal-setting theories once at home. Based on the strategies learned at the hospital, the patient can plan on how to manage activities on her/his own. Moreover, the artifact should allow therapists to add any type of educational content for a specific intervention so the patient can use the artifact as an inventory of educational knowledge. For example:

> *the OT suggests to the patient a type of application that is called Handy Calendar. Now she has to give the link to the patient, and the patient should search for it in the applications bank and download*

> *it. In a cooperative artifact like the one I am discussing, the OT can add the application link and add some tutorial video for it in the session scheduled to talk about the Handy Calendar. Moreover, the OT would have the possibility to connect the session with one or many interventions that could be related to one or many rehabilitation goals. In this case, the patient would have an educational lesson related to the Handy Calendar as a tool to help compensate for memory challenges and remembering everyday tasks. Moreover, it would be education because the patient would learn and become aware that learning the Handy Calendar is part of the intervention to make a plan for when going home and is related to the goal – having a plan for home and better managing everyday life.*

7.4.2 Implications for designing Personal Health Records (PHRs) to use in a rehabilitation hospital

Revising the literature for the right terminology for technologies for giving to the patient control of her/his care and also providing support for a relationship with healthcare practitioners, I landed in the Personal Health Records (PHRs) concept. PHRs are defined as "internet-based, lifelong health records that are controlled by the individual and are meant to promote the individual's engagement in his or her health and healthcare (Tang et al., 2006). PHRs should be controlled by the patients, who should as well enter at least part of the information. PHRs capture well the aim of technology that I have been discussing as needed to support patient empowerment in rehabilitation. That is why I focus on PHRs design characteristics for patient empowerment in rehabilitation.

In Paper VI, I present a list of implications for the design of a PHR for a patient having rehabilitation in a hospital. I present the list in Figure 7.6. These requirements are also compatible with the design needs for the cooperative artifact that support empowering practices in rehabilitation. In Paper VI, we present the design of a PHR for use while the patient is in rehabilitation is a specialist hospital. This is not a common design setting for PHRs. Paper VI is a contribution in this direction.

To highlight among the implications for design for empowerment is the conceptualization of the PHR as a coordination mechanism in addition to being a hybrid information space where both personal and common information spaces are included. Moreover, similar to what was presented previously, providing support for the continuation of the rehabilitation and enhancing the current cooperative artifacts should be considered when designing empowering artifacts. Another implication is considering two different representations for the patient and the healthcare practitioners, which would facilitate each group's graphical needs. Moreover, we have argued in the paper that the PHRs should be tethered to the existing EMRs if we want the healthcare practitioners to embrace them in their work processes. This has been one of the main requirements highlighted by healthcare practitioners during the workshops.

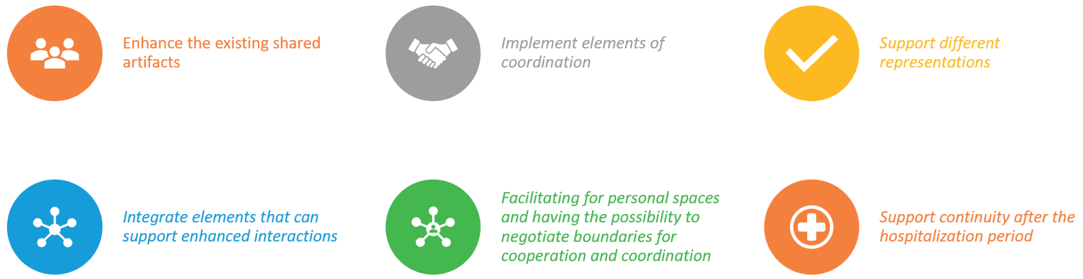


Figure 7.6: Implications for design for a PHR in cognitive rehabilitation in a rehabilitation hospital

7.4.3 Things to consider beyond the hospital

Among the implications for design presented in Figure 7.6 is the continuation and integrity of service. This is one of the most common requirements brought up in each of the workshops. Hence, I discuss some characteristics that an ICT solution that goes beyond the hospital should have based on what patients and healthcare practitioners highlighted as relevant during my study.

In Paper VII included in this thesis, I have presented a thorough review of the concepts of boundary objects and coordination mechanisms as two types of cooperative artifacts. This was presented in Chapter 4. One of the differences is that boundary objects are concepts or artifacts that are used in between autonomous social worlds. Instead, coordination mechanisms are used by semi-autonomous actors within a social world. The actors in coordination mechanisms could belong to the same social world as Bossen and Markussen (2010) state or could be used to coordinate work among actors that belong to different social worlds or communities of practice. In Çarçani and Holone (2019, p. 6) we state:

> "Strauss [] defines social worlds as "... an arena in which there is a kind of organization. Also, each is a "cultural area," its boundaries being" set neither by territory nor formal membership but by the limits of effective communication". In her later work Star uses the concept of "communities of practice" along with social worlds. In Bowker and Star [] they state "We are all in this sense members of various social worlds—communities of practice-that conduct activities together"."

Based on this definition, rehabilitation at home in cooperation with the local rehabilitation facilities and rehabilitation in specialist rehabilitation institutions represent each a social world. As it is now, the two social worlds are independent of one another. When the patient comes to Sunnaas and shares some of the information regarding therapies, tests, materials gathered during local rehabilitation can speed up the process and avoid repetitions. However, not having such information will not prohibit the patient from receiving the service needed from Sunnaas. Nevertheless, the two worlds share documents and communicate and coordinate in different ways in order to make easier the work of both and provide a better service for the patient. Thus, an ICT solution to empower patients in rehabilitation can be conceptualized and designed as a boundary object between the two social worlds or rehabilitation wards/settings.

When the patient is at the hospital, s/he should coordinate with the multidisciplinary team to define and implement the rehabilitation plan. The actors are semi-autonomous because a patient is dependent on the therapists, and the therapists are dependent on the work of one another for interventions where more than one therapist is involved. Moreover, as presented above, an ICT solution to support work in the hospital should make visible the task for patients and therapists and motivate them to take as much responsibilities as it is possible for her/him in the process. Hence, a conceptualization and design of the ICT solution as a coordination mechanism contributes to patient empowerment in rehabilitation.

Leigh Star (2010) while discussing the boundary object concept 25 years after coining it, brings up two main factors that will influence what a boundary object is and what is not. These are the scope and scale in which a cooperative artifact is implemented. Based on my findings in the whole project, I propose that an ICT solution to support cooperation in rehabilitation as a means to patient empowerment should be conceptualized as a boundary object where the information in one social world (local rehabilitation) is made visible to the other social world (specialist hospital rehabilitation) with the patient consent. However, when the ICT solution's scale is diminished to only one social world, the ICT solutions should be conceptualized as a coordination mechanism that can facilitate cooperative work in the social work, make visible patients' and carers' work, and supports negotiation of cooperation when needed.

In the digital goal plan project, both in workshops 1 and 2, healthcare practitioners proposed design ideas connecting such patient shared ICT solutions to their existing EMR systems. For healthcare practitioners is mandatory to report in the hospital EMR. Thus, not integrated solutions would mean double work for them. I argue that such integration is essential for healthcare practitioners to embrace such solutions and contribute to patient empowerment. Otherwise, the ICT solution would be just another patient application that, in time, would not be used. Nevertheless, ERP systems are not integrated in between different healthcare settings. Hence, there is a need for a more in-depth technological integration evaluation.

Another issue to consider in designing an ICT solution for patient empowerment in rehabilitation is considering who would own the solution. In the digital goal plan project, workshop 1, both patients agreed that they wanted to have an ICT solution to get individual login credentials from the moment they come to Sunnaas outpatient clinic. During the time at the hospital, the patient will create health literacy on the usage of the tool and then be ready to use that once moving in her/his own community. The ICT solution should offer flexibility so the patient can add things to the patient's own part of the solution when they are at the hospital and when they leave.

The challenges associated with the development of such a solution in terms of extending the current infrastructure, integrating different systems, and complying with security and privacy requirements go beyond this thesis's scope. My focus has been on defining characteristics for the design of empowering artifacts for patient empowerment in rehabilitation as described by patients and healthcare practitioners.

From January 2021, Sunnaas has been granted the funds to start developing such a solution. They will cooperate with a rehabilitation center in one municipality in Norway. I was involved in writing the application and presenting a summary of my findings regarding requirements for such a solution. The characteristics discussed in this research question provide the ground for the design of such a digital solution. My research project's work presented in this thesis contributes to that digital solution conceptual design.

7.5 Conclusion

In this chapter, I have presented my findings regarding empowering practices for patient empowerment in rehabilitation. The practices listed have been described as relevant by the participants in my study to enable empowerment outcomes for them. Moreover, I have also presented some design implications for cooperative artifacts for patient empowerment in rehabilitation. The cooperative artifacts should support the empowering practices and consider a wider perspective of rehabilitation beyond a rehabilitation ward. The practices and the implications for design should contribute to forward the discussion of patient empowerment. They can also contribute on how to operationalize patient empowerment in practice not only in rehabilitation but also in other healthcare settings. Moreover, at the core of my findings in this chapter is the consideration of patient empowerment in the cooperation between the patient and the healthcare practitioners and studying this cooperation with a cooperative work perspective through CSCW lenses.

Part III

Part III - Concluding

CHAPTER 8

DISCUSSION

> "Once something is answered,
> then there's another question.
> Hence the eternal quest."
>
> *Neil deGrasse Tyson*

In this chapter I discuss my findings in relation to the literature presented in Chapter III and IV. I have investigated empowering practices for patients in rehabilitation and for people with Mild Acquired Cognitive Impairments (MACI) in the co-design process.

I start by discussing how patient empowerment in the rehabilitation process and empowerment of the same patient group in the co-design process are interrelated. Then I discuss if my findings of empowering practices contribute to the empowerment outcomes in rehabilitation and co-design with people with MACI.

Further, I discuss the similarities and differences of empowerment in co-design and in rehabilitation both in terms of outcomes and practices presented in this thesis and reflect on what can be learned from one another. Next, I discuss how the fields of Participatory Design (PD) and Computer Supported Cooperative Work (CSCW) can come together in the design of cooperative artifacts that aim empowerment of a weak user group. Finally, I conclude the discussion by highlighting some key messages of this thesis.

8.1 How empowerment in co-design and empowerment in rehabilitation interrelate?

Empowerment is a developmental and relational concept (Gibson, 1991a), which means that a person or a group can strengthen their position toward empowerment in the social relations that they are involved in. When discussing the empowerment of patients in healthcare, the focus should not be only on developing the patients and increasing their abilities, but also on considering a positive and cooperative patient-healthcare practitioners relationship (Palumbo, 2017; Aujoulat et al., 2007; Small et al., 2013; Chiauzzi et al., 2016). A positive relationship means that the healthcare practitioners are involved in contributing to this patient empowerment in their care. Moreover, they agree to re-conceptualize the relation and division of labor to achieve co-empowerment for both groups.

Information Communication Technology (ICT) has contributed to re-distributing tasks, bringing change in roles, and enabling different kinds of cooperation between people. The same is also present in the healthcare sector, where different applications support the cooperation between healthcare practitioners in managing the care process. However, recently patient applications are emerging that contribute to renegotiating the existing paternalistic relation and empowering the patient in her/his care process (European Patient Forum, 2015).

To design artifacts that will support empowerment outcomes for a power weak group can also benefit by empowering this group in the design process of such artifacts. I have applied a PD approach to investigate empowerment practice in rehabilitation. This implies discussing the practices both with patients and healthcare practitioners - preferably together, where they can negotiate values (Iversen et al., 2012; van der Velden and Mörtberg, 2015). When involved together in co-design patients and healthcare practitioners, a dis-balance of power in most cases prevails in the co-design sessions. The dis-balance in power comes as a consequence of their differences in power/knowledge (Foucault, 1970), differences created by the healthcare social structure (which involves a hierarchical relationship between patients and healthcare practitioners) (Haugaard, 2012), or differences in cognitive or physical abilities.

Hence, the patients need to be empowered in the co-design process to contribute co-construct empowering practices for rehabilitation. Empowerment of the weaker group in co-design would contribute to equal power relations in co-design discussions and, consequently, better empowerment practices in rehabilitation.

Thus, patient empowerment in rehabilitation and empowerment in co-design are interrelated by empowering artifacts that facilitate empowerment in rehabilitation. These artifacts are cooperative artifacts that should be used between patients and healthcare practitioners.

It is not always the case that empowerment in co-design aims and contributes to the empowerment of a user group in the context of the design outcome. For example, in the case of MACI patients co-designing a communication tool with their family members, the focus of the study can be on empowerment of the MACI people in co-design. However, the communication tool *per se* would not aim empowerment of the MACI person. Another example is the paper of Geuens et al. (2018) who presented a study of the involvement of patients and healthcare practitioners in co-design with a focus on balancing powers in design. The authors have introduced a new method to "turn tables" in terms of power relations in such sessions. While the focus is to balance powers in co-design in healthcare, the design's final aim has nothing to do with the empowerment of the patients in their care process where they have to cooperate with healthcare practitioners.

On the other side, patient empowerment in rehabilitation could be researched differently if the researcher is positioned in another paradigm, such as positivism or postpositivism. My positioning in the critical-constructivism (Guba et al., 1994) paradigm brings me as a researcher to study the empowering practices where they are happening and gain knowledge as co-constructed in action. In this paradigm, a PD approach is suitable for getting involved in activities with the patients and healthcare practitioners and engaging them in discussing and reflecting on empowering practices and artifacts. It is this critical-constructivist paradigmatic position, the belief in the democratic process as enablers of empowerment, and respecting people's knowledge of their realities that made me apply PD as the method of research in patient empowerment in rehabilitation. In this situation, the patient's empowerment in co-design to be able to better discuss empowering practices and artifacts is a recursive derivative of patient empowerment in rehabilitation.

In conclusion, both empowerments are specifically inter-related in the topic deeply studied in this thesis, and it does not imply it should always be the case to be studied vis a vis. However, I want to argue that in my study, neglecting the empowerment of MACI patients in the co-design with healthcare practitioners would have compromised the findings of practices and design implications for cooperative artifacts in rehabilitation. Instead, the case of co-designing cooperative artifacts for patient empowerment in rehabilitation was an added value for the study of empowerment of MACI patients in co-design. It provided me with a complex case where I had the possibility to investigate, experiment, and reflect on the empowering practices from different situations - PD sessions within the group and with other groups such as the healthcare practitioners.

8.2 Do the practices contribute to empowerment outcomes?

In this section, I discuss my findings in relation to the empowerment outcomes. I have investigated practices and artifacts that contribute to the empowerment outcome. However, I have not measured the effect that they can have on the outcomes. Thus, the discussion can contribute as a critical reflective mechanism on the findings and their effect in what they aimed, the empowerment outcomes. I start with the discussion of empowerment in co-design and then move to empowerment in rehabilitation.

8.2.1 Empowerment of MACI people in co-design

My first research question was:

RQ1: *What practices contribute to MACI people empowerment in co-design?*

In Chapter 3, drawing on previous research in PD (Bratteteig and Wagner, 2016a, 2014; Simonsen and Robertson, 2012; Bratteteig and Wagner, 2016b; Mörtberg et al., 2010) I argued as empowerment outcomes in co-design sessions: having a say, influencing the decision-making, and influencing the design outcome. I then asked the following sub-research questions:

- **SRQ 1.1:** *What practices, methods, or artifacts contribute to MACI people's having a say and influencing the decision-making and design outcome in the co-design process?*
- **SRQ 1.2:** *What practices, methods, or artifacts contribute to MACI people have a say and influence the decision-making and design outcome in the co-design process of cooperative artifacts with their healthcare practitioners?*

I have answered both questions in Chapter 6. For the first questions, I have described practices and artifacts strengthening the MACI person's co-design involvement. Instead, to answer the second question, I have developed a theoretically drawn method that I have also applied in practice in two workshops and evaluated on its contribution to MACI people's empowerment in co-design. I have also presented the artifacts used for this method. In this sub-section, I discuss how the practices are related to the empowerment outcomes and finally discuss how the practices contribute to balancing powers in co-design by changing the sessions' power dynamics.

The practices that I described in Chapter 6 start with things that should be considered in preparing for co-designing with MACI people. Building a comfortable environment serves as an incentive for MACI people to be more motivated to contribute to the process and have a say.

The other category was the one of motivating the generation of design ideas. This would contribute to MACI people have a say in the design process by enabling and supporting them to articulate their ideas and thoughts and have the possibility to envision future solutions and abstract thinking. Moreover, generating more ideas would contribute to influence the decision-making and the design outcomes because the ideas generated, as stated by Schön (1983), become design choices and the choices are the ones that move the design forward.

I also presented two ways on how the selection and evaluation of ideas were made. Enabling discussion and requiring a limitation of choices to trigger participants to make decisions is a selection technique used in design (for example, in Joshi and Bratteteig (2016) where the process with elderly people has similarities with my PD process). The practices described provide some ways on how to make the MACI people join their ideas and, as a group, influence the decision-making and the design outcome.

Regarding the EquiN method, the method itself aims to give MACI people a stronger voice in the design process through the EquiN cards and the cards' discussion in the horizontal group. Starting as represented statements, supplemented with the group discussion, the patients bring the EquiN cards to the common co-design space with the healthcare practitioners. EquiN cards aim to help MACI people balance powers in the discussion in the vertical group, influence the decision-making and the design outcome. I have evaluated the power dynamics in the vertical sessions. Patients using cards as strength, partners, or only voice show that the method has amplified the patients' voice. Moreover, I found that the patients had contributed to decision-making, and their contribution is visible in the design outcome.

In PD, power relations have been mostly discussed on the level of the whole project. A study that is focused on the dynamics of power in a workshop is the one of Bratteteig et al. (2016). However, when discussing power, the authors go back into reflecting on the whole project. In contrast, in my study, the empowerment focus is on the micro-level of power relations in the co-design sessions. In the EquiN method practice, such micro powers become more visible in the vertical sessions. In such sessions, patients and healthcare practitioners have to discuss together the design of cooperative artifacts that will support and maybe change the way they cooperate now.

The healthcare practitioners have more knowledge than the patient on the patient journey at the hospital, they have more cognitive abilities than a patient with MACI, and they are the professional carers who are trusted to pursue the best for the patient. So, under these circumstances, the MACI patients are in a lower power position than healthcare practitioners. Using power terminology, healthcare practitioners' "power to" influence the outcome is higher than MACI people. Moreover, they have a "power over" the MACI patients when involved in co-design where usually the medical practitioners have been deciding for the patients (Geuens et al., 2018). The "power over" is mainly enabled by differences in the rehabilitation process knowledge and the patient's trust in her/his healthcare practitioners' work.

As stated above, the power in a PD session resides in the ability to move a statement to the final design decision. However, the journey of a statement is long, and factors such as the ability to articulate or represent one's own ideas can diminish the chances of a statement from one person to become part of the design results. A person who already has a set of design ideas is better prepared to argue and gain support from other stakeholders in the PD session, according to Bratteteig et al. (2016). Enabling stakeholders' ability to generate design ideas and standardizing the representation in a way that is suitable for the weaker group gives all stakeholders equal chances to envision future solutions and represent the ideas simply. This contributes to equilibrate their possibilities and increase the weaker user group 'power to' influence the design outcome.

An example of a 'power over' situation is the one when the cards become the only voice of the patient in the decision-making and the design outcome, and healthcare practitioners took one-sided decisions. However, even in this case of power over, the imbalance in power has been amplified with the cards' by giving the patient the possibility to be represented in the design outcome through the cards even when his/her own abilities compromise a dominating position. The patient is influenced or trusts the care professional who makes the final decision. However, the genesis of that decision is still the patient EquiN card, the patient voice or the voice of all the patients that participated in the horizontal group, discussed, evaluated, and selected that specific idea. Hence, the power of the patient and of the healthcare practitioner as a positive-sum has increased, and they both have contributed to the final outcome.

The techniques to generate design ideas, the movement of statements to design ideas within the group, and the usage of the cards in vertical groups show an increase in the MACI people's 'power to' articulate their design ideas and defend them. The usage of cards as discussion partners and as winning arguments and the influence in these cases on the design outcome in the form of "common decisions" or "patient influenced decisions" confirms the advancement in "power to".

The practices and artifacts that I described in Chapter 6 contributed to balancing the power in the workshops where the EquiN method was applied and created an atmosphere of 'power with', where the patient and the healthcare practitioner share power that grows out of collaboration.

Finally, I want to discuss the role of the researcher/designer in these practices. The designer's influence in the co-design sessions' layout puts her/him in a "power over" position due to the ability to ideate and organize the co-design encounters. Moreover, the "power to" is also manifested in the EquiN method when deciding on the statements and the representation of the statements. In the practices in Chapter 6, I have proposed cooperation and mutual learning between the researcher/designer and the domain experts in a field, where the domain experts also become patient representatives. Building a mutual learning relationship with domain experts and maybe patient representatives can balance the powers in preparing such co-design sessions. That can influence in diminishing the designer's "power over" and increasing the possibility of a "power with" relation.

Moreover, in the EquiN method, I have recommended ethnographic studies that a designer/researcher should undertake to get to know more about the context. In this way, s/he would be able to apply the knowledge gained during ethnography to create adequate design ethnography sessions. The ethnography knowledge should serve as a nudge for the MACI patients to open their ideas and design space. Participants should be facilitated to bring these ideas further, change them, or reject and neglect them. The designer can observe those small interactions during ethnography, those tacit moments that make a significant difference and bring them to the MACI patient's attention through the EquiN cards. In this case the researcher/designer do not have a "power over" in the session because it only highlights the reality with the aim to contribute to MACI people's "power to" make decisions in the design space.

8.2.2 Patient empowerment in rehabilitation

My second research question was:

RQ2: *What practices contribute to patient empowerment in rehabilitation?*

In Chapter 3, drawing on previous research on patient empowerment (EPF, 2015; Palumbo, 2017; Chiauzzi et al., 2016; Umar and Mundy, 2015; Small et al., 2013) I concluded in four main empowerment outcomes in patient empowerment: participation in the care processes, understanding the care process and the treatment, gaining control of own treatment, and cooperating with healthcare practitioners. Based on this, I asked the following sub-research questions:

- **SRQ 2.1:** *What cooperative practices contribute to make patients more involved, understand, and in control of their rehabilitation?*
- **SRQ 2.2:** *What are some implications for the design of cooperative artifacts that support patients involvement, understanding, and control in rehabilitation when they cooperate in the care process with their healthcare practitioners?*

In Chapter 7, I have described some cooperative practices for patient empowerment in rehabilitation. The first practice I described is strengthening the patient position in the collaborative articulation work (Hillgren and Linde, 2006; Bagalkot and Sokoler, 2011). The current rehabilitation practices require the patient to be involved in defining their treatment and contributing to the division of labor during treatment. Participation of patients in articulation aims to make them feel more in charge of their rehabilitation process, define SMART goals relevant for them (Evans, 2012) and motivate them to be more involved in the rehabilitation process (Wilson et al., 2002). However, empowering the patients is not only about participation. The other empowerment outcomes should be part of the practices. I found that currently, the patients' understanding and feeling of control of this collaborative articulation of the rehabilitation plan is low and, in some cases, frustrating. Thus, the practice I described is strengthening collaborative articulation and implementing processes and ways to increase patients' empowerment in all outcomes. This means that collaborative articulation in itself enables participation as good practice toward empowerment.

The second practice is "Making activities visible and facilitate overseeing them". This practice is relevant for enabling understanding and control as empowerment outcomes. By making activities visible and facilitating seeing them contributes to making the patient and healthcare practitioners understand the practices that each of them does. Plus, they can adapt their behavior based on the behavior of the others by providing in this way the feeling of control and knowing what one is doing.

Publicly render visible activities and offer the possibility to oversee events and activities has been related to the concept of awareness in CSCW (Heath and Luff, 1992; Heath et al., 2002; Dourish and Bellotti, 1992; Schmidt, 2002b). Awareness is described as a relevant element of making cooperative work possible. I want to argue that awareness, as studied in CSCW, has some similarities and differences in comparison to awareness in patient empowerment.

Patients and healthcare practitioners are new into the cooperative space. Their need to make visible and oversee activities is not the same as in the case of two specialists who have already created awareness. They are two novices who, through the overview and making activities visible, are transitioning toward awareness. The facilitation of the transition to awareness is the one that is actually relevant for patient empowerment. This is different from how awareness has been discussed in CSCW as happening between two experts that understand the environment around them and adjust their actions based on that, such as is in Heath and Luff (1992). However, what constitutes awareness as studied in CSCW can help in the transition to awareness for achieving patient empowerment. That is why making activities visible and providing ways to have access to the overview of activities would be a way to patient empowerment.

Other practices that I have described are the establishment of cooperative artifacts between patients and healthcare practitioners. The relevance of such artifacts has been discussed in the literature previously (Calvillo et al., 2015; van der Heijden et al., 2015; Pagliari et al., 2007). Such cooperative artifacts can facilitate patients' empowerment in rehabilitation by supporting articulation work and supporting to make activities visible and oversee others' activities. In Chapter 7, I have also described the design implications for such cooperative artifacts.

Including transition work and self-management educational work contributes to patients' understanding and control of the rehabilitation process.

Also, I have presented facilitating different types of negotiation as relevant for enabling participation, understanding, control, and cooperation. The different kinds of negotiation should support the flexibility of the cooperation or the necessity for empowerment from each patient. This should allow the patient to adjust participation and control in rehabilitation to her/his capacity. Moreover, enabling negotiation would also give the opportunity to healthcare practitioners to share some of the work with the patients and do this in a continuous way where the distribution of work is discussed.

I have also answered the second sub-research question by discussing some implications for the design of cooperative artifacts to support patient empowerment in rehabilitation. Akeel and Mundy (2019) when describing characteristics to consider for designing technologies for patient empowerment list: access to the care data, become informed and gain knowledge, enable engagement in care, support patients confidence, and target individual needs. These elements are also relevant for ICTs for patient empowerment in rehabilitation. I have listed the support for the practices mentioned above as possible implications for design.

Moreover, I have focused specifically on the design of Personal Health Record (PHR) for cognitive rehabilitation in a rehabilitation hospital. PHRs are considered to have the potential to contribute to patient empowerment (Pagliari et al., 2007). I found that PHRs to be used in hospitals can be conceptualized as coordination mechanisms, which help coordinate the division of labor between patients and healthcare practitioners. However, cooperative artifacts that support patients in rehabilitation should surpass the limit of a rehabilitation ward. In order to make the patient empowered, the ICT solution should be positioned in the hand of the patient who brings it around in her/his journey.

In Chapter 7, I started by presenting an analysis of cooperative work in rehabilitation. A detailed account of such analysis is presented in Paper II. I have positioned that paper in the workplace studied in CSCW (Luff et al., 2000; Schmidt, 2000).

Luff et al. (2000) describe workplace studies as concerned with the practical accomplishment of workplace activities and how tools and technologies feature in work and interaction within organizational environments. Workplace studies position the emergent and reflexive character of practical action at the center of analysis and are relevant in CSCW. Blomberg and Karasti (2012) when presenting different ways of involving ethnography in design, describe such studies as "Ethnography workplace studies unencumbered by design". The study presented in Paper II and the short account that I have included in Chapter 7, belong to these category of ethnography.

The cooperation in rehabilitation is a new context in workplace studies, which can contribute to CSCW by its complexity of cooperative relations. Schmidt (2000, p. 4) argues for the relevance of workplace studies stating that "the primary role of workplace studies in CSCW is thus to dismantle the common-sense conceptions of cooperative work, take them apart, unpack and disclose the hidden practices of articulation work, and thus give us access — analytically and conceptually".

Paper II and this thesis contribute in this direction. The detailed patient vignette presented in Chapter 3, created as a summary of all the findings during the ethnographic study at the hospital, uncovers the cooperation dynamics in rehabilitation. Schmidt also states it is the theoretical contribution of workplace studies and not their list of final requirements for technologies that is the most important. The conceptualization of "recovery pathways" brings a new perspective on the way healthcare can be organized. The focus on people functioning in everyday life is relevant even in the case of acute care. A heart problem will change people life and without adopting the lifestyle would be difficult to manage the situation. Thus, the recovery pathways, go beyond the traditional rehabilitation settings.

Finally, I want to highlight the role that CSCW lenses have played in looking at empowerment in rehabilitation. I argue that looking at the patients-healthcare practitioners' relationship as cooperative work as defined in CSCW (Schmidt and Bannon, 1992) has contributed to analyze and understand practices for patient empowerment which has not been related to patient empowerment in previous studies.

Studying patient empowerment from a cooperative work perspective highlights the relevance of cooperation and considers the challenges and disagreements both from patients and healthcare practitioners. Moreover, like in Strauss et al. (1985) in the book "Social organization of medical work," I look into the sociology of work and sociology of care in the rehabilitation setting. This contributes to situating the discussion of patient empowerment in practice in terms of work arrangement. This is an addition to the models of rehabilitation such as Wade (2020, 2009); Scotland (2007) and enters into how the relationship between patients and healthcare practitioners can be regulated in different parts of the rehabilitation process.

In my study, I have conceptualized the rehabilitation model presented in 2.1 by Wade (2020) from a work organization perspective. Even though my intention was not to contribute to the clinical aspect of rehabilitation, the organization of rehabilitation as planning recovery pathways and situated recovery pathways where each recovery pathway represent a rehabilitation goal can contribute to Wade (2020) rehabilitation model because it describes a more holistic perspective of the rehabilitation.

8.2.3 Reflections on measuring empowerment

I looked at empowerment as a multi-dimensional component in which empowerment outcomes, empowering practices, empowering artifacts, and empowerment values are included. I reviewed the literature for empowerment outcomes and applied the outcomes to study the practices that I present in this thesis.

In this chapter, I presented reflections on how the practices that I have described contribute to the empowerment outcomes. Thus, I can argue that I have applied the empowerment outcomes as the measurement factors for what empowerment means or what it needs to achieve and the recursive reflection in this chapter as a way to consider how the practices contribute to the outcomes. That is also how Zimmerman and Warschausky (1998) have described empowerment outcomes and the relation with empowering practices.

I have introduced some measurements in evaluating the EquiN method in Paper V where I have presented some analysis measures for studying power in terms of influence in decision-making and the design outcome. Additionally, the studies that I presented in Research Blocks have been incremental, so the practices defined in the first Research Block 1 have been reevaluated by the participants of the study in Research Block 2.

8.3 Empowerment in rehabilitation and co-design - similarities and differences

In this subsection, I discuss the two empowerment contexts that I study in this thesis. I have described in Section 1, how they interrelate with each other, and now I reflect on where they meet or differ.

As empowerment outcomes in PD, I have concluded in participants’ having a say in the design process (not only having a voice and being part of the design process but generating design ideas) and "influencing the outcome". Influencing the outcome includes influence decision-making in the design process and influence the design outcome (Bratteteig and Wagner, 2014). Indeed, the three outcomes are related to each other, and an empowered person in co-design owns all the three outcomes. These empowerment outcomes are similar for all the participants in the co-design process. However, they are especially enabled when the stakeholders have differences in knowledge, differences in cognitive and physical abilities, or power dis-balances due to existing social structures that imply some hierarchy. In that case, the aim is to enable the empowerment outcomes for power weak participants to balance their power with others in the co-design sessions and the overall PD project.

In the patient empowerment discourse, it is clear that the aim is to empower the patients. I summarized the empowerment factors (Chiauzzi et al., 2016), elements (Palumbo, 2017), discourse areas (EPF, 2015) in three main empowerment outcomes: a) The patient participates in the decision-making regarding her/his care. Participation, in this case, is a process that means being involved and being an active member, and having the opportunity to influence the decision-making. b) Have an understanding of the treatment and the care process. This means gaining health literacy that the patient can use to influence the decision-making and to be able to self-manage her/his own situation. c) Gaining control of your own care process - This means being able to contribute, share decisions with healthcare practitioners, and be able to manage your own care process. This is associated with a feeling of ownership of the care process.

When comparing these two contexts of empowerment outcomes, they share similarities. Having a say and participation represent the same aim of being part of something and having the possibility to influence the outcome of that.

Influencing decision and design outcomes is compatible with gaining understanding and having control of the process. The one that is not visible in the outcomes of empowerment in co-design is the part of gaining understanding. This is not something that is not taken into consideration in PD. The principle of mutual learning is central in PD, which is related to understanding and exchanging values among all the stakeholders involved in design (the designer and all the user groups represented). As I have argued in Chapter 3, mutual learning enables the influence in decision-making and in the design outcome. The same as understanding is a crucial characteristic of control.

Hence, empowerment in the two contexts I have investigated is represented through different terms that are more relatable to each context. However, they share the same values and represent the same things. This is not news as these empowerment outcomes are connected to what Zimmerman (1990) described as a) personal competencies, a desire for and a willingness to take action, b) gain mastery and control of own life, and c) democratic participation in the social environment.

One relevant aspect of empowerment that is highlighted in the case of patient empowerment is the consideration of the cooperative relationship between the patients and the healthcare practitioners. It is in the cooperation and through cooperation and negotiation of cooperation that the other empowerment outcomes can be enabled. Cooperation and collaboration has been associated with empowerment by other authors (some examples (Kinnula et al., 2017a; Bond and Keys, 1993)). Looking at empowerment in the cooperative relationship and the cooperative work between the interested groups can make possible a more evolutionary change where all parts agree. In the case of patient empowerment in rehabilitation, this was possible because all parties accepted the empowerment values, and they were willing to find better ways to cooperate. If the empowerment values are not present and the one in power wants to dominate, more revolutionary approaches may be adequate. With its democratic principles and equal power relation, PD represents cooperative empowerment, where people exchange and negotiate views and values.

8.4 Bringing together CSCW and PD

In this thesis and Paper V, I have contributed to developing a PD method that considers the participation of users in the design process and their influence in decision-making. However, EquiN is useful in the design of cooperative digital solutions between two user groups that have power imbalances influenced by social structures, knowledge, or abilities. The method contributes to the negotiation of cooperative work between parts and the design of technology(S) that can support the new negotiated cooperation. Hence, EquiN method is a method for the design of CSCW tools. EquiN is a method that seats between the two disciplines as concerned with power issues in design and the design of cooperative artifacts that support a cooperative work setting.

In Chapter 4, I presented a review of the literature on how different authors have drawn the lines between PD and CSCW (Grudin, 1991; Kensing and Blomberg, 1998; Bratteteig and Wagner, 2016a). All highlight the focus of PD in the democratic design process and the focus of CSCW in designing for cooperative work. PD can be a design approach for designing CSCW tools, or PD can be a case study for CSCW to study different stakeholders' cooperative practices in design.

In my study, CSCW and PD meet under the pursue for empowerment. Two groups that cooperate with each other for achieving a common goal can have dis-balances in power. In such a situation, if the aim is to empower the weaker user group in the cooperative space, then a PD approach to the design of cooperative artifacts is needed. PD provides both groups the opportunity to share values and create mutual learning and is concerned with empowering the weaker group in design so those people can have a say and influence decision-making and design outcome. In this case, the design outcome would be a renegotiation of the cooperation and the design of artifact(s) that can support the new cooperative work.

Thus, when the aim is to design a CSCW tool where there is a dis-balance of power among people cooperating, applying a PD approach is recommend. Additionally, PD should consider the empowerment of the weaker group also in the design process. The EquiN method subscribes to such a merge between PD and CSCW.

Despite the EquiN method, this thesis also contribute to both fields, and the research described provides a case where the two fields have been brought together. Hence, the thesis adds to that range of research that sits on both fields.

8.5 Conclusion

In this chapter, I discussed my findings in relation to some of the literature presented in Chapters 3 and 4 that created the theoretical ground for my research. I conclude that the empowering practices that I have described contribute to the empowerment outcomes. Moreover, I have discussed empowerment in co-design and empowerment in rehabilitation as they are interconnected with one another in my research and also how the empowerment outcomes for each are compatible with one another. Finally, I have discussed how this research contributes to both CSCW and PD, representing a case where both fields combined can contribute to better results.

CHAPTER 9

CONCLUSION

> "In literature and in life we
> ultimately pursue, not
> conclusions, but beginnings."
>
> *Sam Tanenhaus*

Now that I have arrived at the end of my PhD quest, I want to summarize relevant parts of the quest and the journey. In this thesis, I have presented my work in the cross-section of Computer Supported Cooperative Work (CSCW) and Participatory Design (PD) in the domain of patient empowerment in rehabilitation and the empowerment of people with Mild Acquired Cognitive Impairments (MACI) in the co-design of cooperative artifacts to use with their carers. I present a summary of the research and contributions in the next section. I conclude with some reflections for further research.

9.1 Summary and Contributions

I have raised two research questions in this thesis.

> **RQ1:** *What practices contribute to MACI people empowerment in co-design?*

and

> **RQ2:** *What practices contribute to patient empowerment in rehabilitation?*

I have built on Zimmerman and Warschausky (1998) empowerment theory where empowerment is seen as a multidimensional and multi-level concept where the dimensions are: empowerment values, empowerment outcomes, and empowering practices. I have argued that empowering artifacts should be included as dimension in empowerment, considering technology's role in enabling different forms of empowerment.

As noticeable by the research questions, I have looked at empowerment in the context of patient empowerment in rehabilitation and empowerment of people with MACI in the co-design process of cooperative artifacts.

I have reviewed and interpreted the literature on the empowerment outcomes for both contexts, and I have empirically investigated empowering practices and artifacts that enable empowerment outcomes in such contexts.

I have found as empowerment outcomes for co-design: participant having a say in the process, influencing decision-making, and influencing design outcome As empowerment for patients in rehabilitation, I have concluded in: patient participating in the decision-making regarding treatment, understanding the treatment and the care process, and gaining control and self-management.

I have investigated practices and artifacts that contribute to such outcomes in both contexts. Thus, for each question, I have included two sub-questions. In order to answer the sub-research questions, I have taken a PD and ethnographic approach to collect data in four research blocks. I have partially presented my findings in each of the selected papers, and I have merged the findings and answered the research questions in Chapters 6 and 7. I summarize the contributions of my research in the following paragraphs. I have grouped the contributions in theoretical ones, referring to the general knowledge I gained, and practical referring to some contributions related to the work that I have done at Sunnaas and how that was made useful for them.

9.1.1 Contribution to Theory

This thesis's theoretical contributions have been in two directions: in the domain of interest - patient empowerment in rehabilitation and the theoretical perspectives - the Computer Supported Cooperative Work (CSCW) and PD.

Major contributions of the thesis are:

1. the practices for conducting PD with MACI people and empowering them in the process (Chapter 6, Section 6.2-6.3)
2. the EquiN method and the EquiN cards as a method suitable for balancing powers in the co-design of cooperative artifacts when MACI people are involved in co-design with their carers (Chapter 6, Section 6.4-6.5)
3. the practices for empowering patients in rehabilitation in cooperation with healthcare practitioners (Chapter 7, Section 7.2-7.3)
4. implications for the design of cooperative artifacts that serve as empowering artifacts for patient empowerment in rehabilitation (Chapter 7, Section 7.4)

Some other contributions are:

The concept of "recovery pathway". This concept brings a new perspective on the organization of work and cooperation in healthcare. The recovery pathway is the totality of work and carers that, together with the patients, work into achieving a functioning goal related to the patient's everyday life. This involves managing the illness and other environmental and social aspects of the patient's life that the clinical condition has influenced. This concept can bring new insight into healthcare work.

I have also described two cooperative artifacts used between the patients and healthcare practitioners. Moreover, I discussed that expanding the existing common information spaces between healthcare practitioners to include the patients and patients work, contributes to patient empowerment.

I have argued the conceptualization of Personal Health Records (PHRs) as a coordination mechanism where the patient has clearly defined tasks and work activities that need to do. Patient work can be taken over and done by healthcare practitioners when the patient is not able to do the tasks, but the visibility of the patient tasks contributes to patient awareness of the rehabilitation process her/his own required contribution and consequently empowerment.

I have presented a table with some main categories to consider for analyzing the Boundary Objects and Coordination Mechanisms. Both concepts are widely used in CSCW, and a review of each of them was missing, altogether with a possible discussion of their differences. Young CSCW researchers can make use Paper VII as a reference for creating an understating of each of the concepts and possibly using them adequately.

I contribute to CSCW with the discussion of some implications for the design of an Information Communication Technology (ICT) that supports patient empowerment in rehabilitation. Dourish (2006) states that CSCW research should not always finish with implications for design. Despite agreeing with Dourish view, my research could not deviate from what I received as a comment from one of my reviewers in the first submission round for the ECSCW (European CSCW) conference, "classical CSCW papers include an implications for design" list. In my research, the implications for design were part of the aim from the start and not an addition to please the CSCW expectations. The implications for design contribute to develop such computational cooperative artifacts and study them in practice in the near future (I talk more about these plans in the practical contributions).

I have contributed through a "method story" on doing PD sessions with MACI people by presenting a detailed account of the process, preparation, tools, techniques, reflections-in-action, and reflection-on-action in three workshops.

I have also contributed with guidelines for conducting PD with MACI people. As MACI people's symptoms can be common with other patient groups, the guidelines can also be considered for others. I have applied the guidelines and practices described in this thesis to design cooperative artifacts for supporting cooperation in rehabilitation. Nevertheless, the guidelines can be useful in other cases and contexts that digital solutions for MACI patients should be designed.

In conclusion, I have contributed to a) patient empowerment in rehabilitation, b) to CSCW by presenting a study of cooperative work in a new setting under-researched in CSCW, c) in PD for bringing the attention to MACI people also under-researched in PD, and d) in PD and CSCW when it comes to the design of cooperative artifacts for cooperative agents that have dis-balance in power and this power issues should be considered in the design process in order to contribute to better empowering cooperation.

9.1.2 Contribution to Practice

During my research, I have also contributed practically at Sunnaas Rehabilitation Hospital.

The first contribution was redesigning the goal plan document and developing a new prototype still in use at the Cognitive Rehabilitation Department (CRD). The new design of the goal plan emphasized once again that we need a digital version of the goal plan. Based on the knowledge gained in the redesign project, the Høgskolen i Østfold (HiØ), in collaboration with Sunnaas, got involved in an Interreg funded project called VITAL: FOR THAT GOOD HEALTH. The aim of the project is to develop a prototype that will be a proof of concept for a tool that can support patient empowerment in rehabilitation at Sunnaas, support patients' participation in the process, and strengthen the cooperation with the healthcare practitioners. The funds granted in this project were used for further investigation of needs and also the initial design for such a solution. Both Sunnaas and Østfold University College (HiØ) are partners in this project. I, as HiØ representatives, worked closely with Sunnaas employees to investigate needs.

Finally, the VITAL project initiated a bigger discussion in the hospital regarding the need for such a solution. I have been in continuous contact with an IT specialist at Sunnaas and the Innovation Office to request additional funds that could support the development of the cooperative artifact that would cover all the implications for the design described in this thesis. Hence, we submitted an application for developing such a digital solution that would support patient empowerment in rehabilitation in terms of: better management of the rehabilitation plan at the hospital and in the local communities and the integration of this solution with the appropriate systems in the hospital and in at least one local community rehabilitation setting. Sunaas have been granted 10 million Norwegian kroner. I contributed to the description of needs through my research insights. I am part of the working group, and we will soon plan further research activities. The discussion generated at the hospital due to my research was a strong contribution to mobilizing the hospital resources in searching for this funding and being deeply involved in the issue of patient empowerment in rehabilitation.

9.2 Future Work

In future work plans, I want to initially notice that I want to continue my research on the findings presented in this thesis. I have also stated earlier in the thesis that the practices described here can serve as a ground for further discussion or other practices that can facilitate empowerment in rehabilitation or co-design with MACI people. I am planning to continue my research in experimenting with the practices in other cases. Besides this "teaser of the future" (in analogy to my technique called "the teaser of future envisioning), I find it relevant and will continue my research on two new directions:

- studying the involvement of MACI people in co-development of technologies and applying high fidelity toolkit to enable their empowerment in the process
- develop the cooperative artifacts which characteristics have been listed in this thesis, evaluate the effect in practice and investigate the design-in-use

The last funded project that I listed above in my practical contribution and my involvement in it will allow me to pursue the interest in both topics presented above.

Part IV

Part IV - List of Papers

PAPER III

INTSYS20

Çarçani, K., and Holone, H. (2020). Guidelines for Participatory Design with People Living with Mild Acquired Cognitive Impairments. International Journal on Advances in Intelligent Systems. ISSN 1942-2679. 13(1&2), pp. 59-84

Guidelines for Participatory Design with People Living with Mild Acquired Cognitive Impairments

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***Abstract* –Mild Acquired Cognitive Impairment(s) (MACI) are called invisible impairments. This invisibility of symptoms makes that researchers often overlook people with MACI. This is the case in the field of Participatory Design (PD). In this paper, we investigate how to involve people with MACI in designing together digital solutions meant for them. Hence, how to involve people with MACI in Participatory Design. Considering the lack of literature in PD focused on MACI patients, we conducted a borderer investigation of the literature and derived a set of guidelines proposed by PD practitioners for involving people with cognitive impairments in PD. We have collected data on conducting PD with MACI patients from two empirical cases as part of two projects in a rehabilitation hospital in Norway, which offers specialized rehabilitation to people with MACI. We conducted 5 PD workshops with three different workshop outlines. Seventeen people with MACI participated. We present a detailed list of reflections-on-action for each workshop outline. We discuss the reflections with findings from the literature and conclude with a list of guidelines that researchers and designers should consider when involving people with MACI in conducting PD. The paper aims to attract the attention of PD practitioners to the MACI user group with the possibility of expanding the guidelines list in the future.**

Keywords-Participatory Design; Mild Acquired Cognitive Impairments; Guidelines.

I. INTRODUCTION

There is an increase in chronic diseases in our aging society, and technology is considered as one of the means to cope with the increasing number of people living with chronic conditions. A notable case is individuals with Acquired Brain Injury (ABI) affecting cognitive capacities. For this user group, the use of technology has become a fundamental part of their daily lives by providing a wide range of useful services and tools to use at home, work, or anywhere else. This paper expands on previously reported results on how to involve people with ABI in designing new technologies that can facilitate their everyday life challenges [1]. Intensive research is ongoing regarding technologies that support patients with moderate or severe cognitive impairments (i.e., [2][3][4]). However, less attention had been paid to people suffering from mild cognitive impairments after an Acquired Brain Injury (ABI), even though mild acquired cognitive impairments are a critical global public health problem and listed among the major causes of permanent impairments [5][6]. In this paper, the abbreviation “mild acquired cognitive impairment(s)” (MACI), coined from Eghdam, Scholl, Bartfai, and Koch [7], will be used to refer to these people. Note that this is not an official abbreviation for the clinical condition. MACIs are usually described as invisible impairments and might include problems with memory, attention, executive functioning, language, and fatigue. People suffering from MACIs typically have a very challenging daily life, given the invisible nature of the condition.

An essential factor for the design of new technologies that can assists MACI people is their involvement in the design of these solutions that will be used by them in the future. User participation constitutes the core of Participatory Design [8]. PD is that design approach that promotes the involvement in the design process of everyone that will be influenced by the newly designed technological solution. Thus, new technologies aiming to assist individuals who have had an ABI would, from a PD perspective, require people with MACIs to be involved in the design process. However, involving people that have cognition problems to envision future solutions or discuss abstract terms is challenging. PD researchers should consider how to promote involvement and participation. The research question we raise in this paper is *What should be taken into consideration when conducting Participatory Design with people with MACIs?*

PD has, in decades, been concerned with marginalized groups and research on how to involve people with dementia, aphasia, amnesia, cognitive impairments, elderly, etc. in the design of new solutions. While the case of people with MACI is different from these diseases, some symptoms are similar. Thus, a look into the existing literature and how other researchers have described guidelines for working with user groups similar to MACI is relevant for building preliminary knowledge. In this paper, we initially present a summary of guidelines for involving people with cognitive impairments in PD projects. The guidelines are from a systematic literature review conducted by the authors of this paper. The findings were cross-checked and refined with the findings of a literature review of conducting PD with people with dementia by Hendriks, Truyen, and Duval [9].

Further, we present two empirical cases of conducting PD with MACI people. We take a reflective practitioner analysis approach to derive a set of reflections for involving MACI people in PD. These reflections, which emerged from the empirical data from 5 workshops with a total of 17 MACI patients as participants, have been further cross-analyzed with the list of guidelines found from the literature. The cross-analysis is also influenced by the literature on MACI people, their symptoms, and advice for leaving with cognitive challenges from medical practices. We have concluded with a list of guidelines for conducting PD with MACI people.

We contribute by expanding the knowledge of conducting PD with a special user group like MACI people who represent a huge share of the society [6] and can benefit from technology to facilitate their daily life. Moreover, we contribute by bringing the attention of the PD researcher to this user group, which due to the "silent" characteristics of the disease, are usually forgotten or overlooked and left alone to fight a challenging daily life.

The next section gives a more detailed overview of the user group, the symptoms they have, and some suggestions from the medical perspective on how the MACI people can adapt their life to the cognitive challenges. This is followed by a section on what PD is and why it is relevant to conduct PD with MACI people. We present a detailed summary of guidelines deriving from previous research on conducting PD with people with cognition challenges as part of our background literature. Further, we describe our methods for collecting the data and analyzing it, followed by the empirical material from two projects done with MACI people. We describe three workshop outlines applied in 5 PD workshops in the two projects. A list of methodological reflections [10] follows each workshop outline. We further analyze and discuss the findings from the empirical cases with the data from the list of guidelines coming from the literature review. In conclusion, we present a set of guidelines for conducting PD with MACI people.

II. MILD ACQUIRED COGNITIVE IMPAIRMENTS AND THE IMPLICATIONS IN A PERSON'S LIFE

In this section, we first describe what it means for a person to live with MACIs. Further, we define what cognitive rehabilitation is and how this service is offered in a rehabilitation hospital in Norway, where we conducted our research.

A. What does it mean to live with Mild Cognitive Impairments (MCI) after Acquired Brain Injury (ABI)?

Cognition is the individual's capacity to acquire and use the information to adapt to environmental demands [11]. However, cognition can be challenged, and cognitive impairments can surface [12]. Cognitive impairments may be associated with cognitive decline due to aging, more-serious decline as dementia, or can be the consequence of an ABI. The latest is the category of patients involved in this study.

ABI is brain damage acquired after birth. The causes of ABI can be from non-traumatic brain injury (i.e., stroke, brain tumors) and traumatic brain injury (i.e., accidents, falls). It can affect cognitive, physical, emotional, social, or independent functioning. The consequences can vary from mild to severe [13]. We specifically focus on those people who have been affected in mildly their cognitive functioning. Eghdam, Scholl, Bartfai, and Koch [7] and Nilsson, Bartfai, and Löfgren [14] use the term Mild Acquired Cognitive Impairment(s) (MACI) "*to describe a subgroup of patients with mild cognitive impairment(s) (MCI) who are expected to reach a stable cognitive level over time. This patient group is generally young and have acquired MCI from a head injury or mild stroke*" (ibid). As this is similar to the user group we are interested in this paper, we borrow their terminology.

Cognitive impairments often persist after the ABI, and they can significantly affect an individual's abilities to perform everyday tasks, fulfill previous roles, and maintain personal-social relationships [14][15][16][17]. Thus, people's life becomes challenging, based on the severity of their injury. These people can experience difficulties in cognitive and emotional processing while having no or limited movement disorders and being independent in self-care [14][18]. Cognitive impairments after a brain injury can cause the following problems to people:

- They can feel a lack of energy for doing many things within a specific time frame.
- They can face problems with memory, which can be related to working memory or long-term memory. This creates difficulties in remembering and learning new things.
- They can face problems to keep the attention and concentrate on a specific issue and be able to eliminate the other unimportant information around them.
- They can face a reduced tempo of performing activities and engaging only those activities that are relevant to them.
- They can face a reduced multitasking capacity. The person becomes very tired if s/he has to manage too many activities at the same time.
- They can face an increased response time due to a slower process of thinking.
- They can face difficulties to start or initiate something, sometimes caused but a lack of motivation.
- They can face challenges in making mental changes from one topic to another.
- They can face difficulties in stopping, which relates to impulsivity, overactivity, and difficulties in controlling unwanted or inappropriate responses.
- They can face a reduced understanding of oneself, which involves a reduced ability to perceive one's own mistakes, to take into account the impression one makes on others, or to assess a social situation accurately.
- They can face thinking specifically and taking everything literally. This can also be associated with a loss of the ability to plan, look ahead, and think purposefully.
- They can have difficulties with using language and communicating, such as not finding a word, repeating the self in a conversation, having difficulties in making a point in a conversation, mixing words, or having difficulties in understanding humor or irony.
- They can face difficulties in processing the information received, solving problems, and executive functioning.
- They can face changes in how they engage in social life and social communication.

(the list presented above is a translated summary from [19][20])

The list of cognitive challenges that can be faced by patients that have had an ABI and suffer cognitive impairments shows how heterogeneous this user group is. In MACI people, these symptoms are mild, and the person in most cases continues having an active life, working or participating in social activities, running a house, or following hobbies. However, their life is not the same [21].

The symptoms of MACI patients mentioned above have similarities with other user groups as dementia and amnesia when memory problems are present, aphasia when communication problems are present, executive functioning, memory, attention, reduced tempo, and slow reactions are elements that are also associated with getting old. Moreover, problems with problem-solving can be similar to other cognitive impairment that patients have had from birth.

In the following subsection, we will describe the case of cognitive rehabilitation as the setting on which we conducted our research. In this paper, we have used interchangeably different variations to refer to people living with MACIs, such as "people with MACIs, MACI people or MACI person". Instead, from now on, we will use "patient(s) with MACIs, or MACI patient(s)" to refer to people with MACIs who are patients in a rehabilitation institution, which is the setting of our study. Moreover, in some cases, we will use the term patient(s) even when referring to the home context because people with MACI have a chronic disease, which makes them chronic patients in a rehabilitation context. When we describe our case, present the findings, and discuss them, we use the term "patients" as it better represents our participants. Instead, when we present the final guidelines, we refer to MACI people in general in any setting where they can be involved in designing new technologies useful to them.

B. MACI Treatment – Cognitive Rehabilitation

"*Cognitive rehabilitation can be defined as a learning experience aimed at either restoring impaired higher cerebral functioning or improving performance in the real-world using substitution or compensation techniques*" [16]. Cognitive rehabilitation is offered in specialized rehabilitation institutions. The cases presented in this paper are related to two projects that we did in collaboration with the Department of Cognitive Rehabilitation (DCR) of Sunnaas rehabilitation hospital in Norway.

Sunnaas offers multidisciplinary rehabilitation to people with complex functional impairments following illness or injury. We focused only on the cognitive rehabilitation process. The rehabilitation at the hospital (inpatient) is carried forward by a multidisciplinary team that helps the patient to define realistic and attainable rehabilitation goals and then define, in collaboration with the patient, a set of interventions that the patient should do for achieving the goals. The goals and respective interventions make a rehabilitation plan. The rehabilitation plan is imprinted in the "Goal-Plan" document. This Goal-plan is at the core of the rehabilitation process in the hospital. It helps to coordinate the activities that both the patient and the multidisciplinary team get involved in during the patient's hospitalization period. In every activity at the hospital, both the multidisciplinary team and the patient should refer to the Goal-Plan. For the team, the Goal-Plan resides in the hospital Electronic Medical Record system. Instead, for the patient, the Goal-Plan is a printed paper document. The patient continues with the rehabilitation plan at home and returns to the hospital after 2-6 months for short follow-up and further adjustments of rehabilitation goals. A more detailed description has been presented in Becker, Kirmess, Tornås, and Løvstad [22].

As part of the rehabilitation plan, different kinds of rehabilitation therapies, customized to each patient's needs, are applied. Some suggestions of rehabilitation techniques for working with patients that have had an ABI retrieved from the literature are:

- When communicating with an MACI patient, it is important to give her/him time, use short and concrete sentences, be clear, and try to receive confirmation that s/he understood what was said. Moreover, it is relevant to pay attention to how the patient feels that day.
- In order to increase understanding, remembrance, and better communication with MACI patients, repetition is necessary.
- Giving patients more time to do things or discuss is another strategy suggested. Moreover, considering the low capacity and high level of fatigue, pauses are recommended [19][20].
- In order to improve executive functioning Haskins, Cicerone, and Trexler [23] highlight the Goal-Plan-Do-Review (GPDR) model as helpful. GPDR requires the patients to increase awareness toward a specific goal that they want to achieve, plan carefully on how to achieve this goal, do the activity, and evaluate that after.
- In order to improve memory deficiencies, Haskins, Cicerone, and Trexler [23] describe different techniques which are in analogy with a "divide and conquer" approach where a bigger task is divided into smaller steps, and these steps are used to train by repetition. Considering that memory is fragile, an errorless approach in the rehabilitation techniques is used [18]. This aims to teach the patients only the right things so s/he might not risk preserving the error instead of the right information. Visual cues are also considered useful in helping to train memory deficits [24]. Cicerone et al. [25] suggest using references from patients' daily life because it is easier and more likely to remember the information when it is silent and personally meaningful.

The techniques mentioned above were both presented as in individual therapy sessions or group therapies. Patients with MACIs can find group therapies specifically helpful when it comes to discussing their problems and expressing more about their story in front of other patients with similar challenges. Now that an overview of the patient group symptoms and the rehabilitation process which s/he goes through has been presented, we further describe PD and how that might be relevant for this user group.

III. PARTICIPATORY DESIGN

PD was established at the end of the 1970s to democratize both the working life and the design process of new information technologies [26]. PD emphasizes the idea that those who will be affected by the design of new information technologies or digital artifacts, should get involved and have a say during the design process of these technologies [27]. PD considers users "domain experts" of the realities in which they live, so they must undertake the role of the designers [27].

In Routledge Handbook of Participatory Design, Simonsen, and Robertson [8] define PD as:

"*a process of investigating, understanding, reflecting upon, establishing, developing and supporting mutual learning participants in collective "reflection-in-action". The participants typically undertake the two principal roles of users and designers where the designer strives to learn the realities of users' situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them.*"

At the core of PD is the idea of genuine participation in decision making. Genuine participation stands on a political rationale where the voice of marginalized groups is heard in the decision making that will influence them. Thus, designing technologies for patients with MACIs require their participation in the design process. Their marginalized voices in a paternalistic healthcare system where the patient follows what the doctors say should be raised and heard. By applying PD, these patients can have a say and genuinely participate in the design of new technologies, which will be used by them.

Moreover, as we describe above, MACI is a silent condition and often overlooked. This makes this group marginalized for the technologies that have paid more attention to more severe cases. We use the general term "technology(s)" because, in every technology type, digital solutions, tangible solution, ICTs (Information and Communication Technologies), etc. people that will be influenced by the new technology should be involved in its design. Moreover, different technologies can help MACI patients in different situations. For example, a tangible alarm button can be used in the case of a fall. Instead, an application can be designed to serve as a calendar.

PD is applied as a set of general principles that should be adapted to the specifics of the project. One of the principles of PD is "equalizing power relations". Thus, PD is concerned with questions such as "whom we may risk leaving out of the design space, how we can act upon such challenges and how to provide for alternative perspectives on participation and democratization" [28], and finding ways to give voice to those who may be invisible or weaker in organizational power structures [29] and beyond, thus building a democratic process.

Greenbaum and Kensing [29] point out that democracy is often propagated as a concept that is assumed to happen by itself. However, it requires educated and engaged people acting on their own interests and in the interests of the common good. Another principle of PD is mutual learning, where both designers and users should learn from each other in the design process. Learning also is cognitively demanding. Thus, the requirement for active participation and mutual learning poses a requirement for people to have a certain level of cognition. The number of people who live with cognitive impairments is high. To have a truly democratic process, we should not risk leaving this user group out of the design process.

Greenbaum and Kensing [29, pp. 33-34] have listed tools and techniques among the principles in PD. Different tools and techniques are used by designers and researchers to involve users in the design process. The designer should reflect which tools and techniques fit her/his user group and then adapt them with the practice at hand [30]. Choosing the right techniques and tools is as relevant as challenging when the focus group of the research is people who suffer cognitive impairments. A technique's goals, structure, and participation model can pose cognitive requirements to the participants. Some aspects of these requirements are fundamental to the activity (for example, a group discussion must involve communication), while other aspects are flexible (communication can be verbal, gestural, etc.). This flexibility can suggest ways in which a technique may be modified or adapted to people's cognitive abilities. However, what tools and techniques are chosen in a PD project would influence the true level of participation of the users in the design process [29].

A. Participatory Design with people with ABI

In PD, the active participation of people with disabilities in designing new technologies has been discussed significantly in conferences and workshops. Dementia patients or specific severe clinical conditions affecting cognition have been in the focus of many publications (examples [31][32][33][34]). Regarding the mild cognitive impairments, extensive research has been done with old adults or people with intellectual disabilities. However, little research has been conducted specifically on patients suffering from MACI [1] [35].

Augstein, Neumayr, Ruckser-Scherb, and Dielacher [36] have designed an interactive tabletop in the rehabilitation setting of people after an ABI by using a PD approach. However, they have involved in the design rehabilitation specialist as proxies of people that have had an ABI.

More research has been conducted with people that had a stroke. Balaam et al. [37] and Threatt et al. [38] have described some cases of involvement of stroke patients in the design process. However, this involvement is mostly in terms of interviews and observations and further during testing. The design is handled either by the designers or designers and clinicians together. The involvement of clinicians in design is as well described in Faria and Sergi Bermúdez [39]. Instead, Magnusson et al. [40] describe a case where stroke patients are involved in focus groups and as well in co-design workshops were brainstorming, and body-storming techniques are used.

Table 1. List of guidelines for conducting PD with people with cognitive impairments

No.	Guidelines	Reference
DG_PP1	Get the consent of the participant on various moments throughout the research process	[9]
DG_PP2	Communicate about project goals without intermediaries	[9]
DG_PP3	Give yourself enough time for general practicalities	[9]
DG_PP4	Get to know your target group, try to understand their cognitive deficit and become sensitive to their needs and situation	[9][41][42]
DG_PP5	Assess abilities through standardized tests	[4][9][43]
DG_PP6	Recruit and plan well in advance	[44]
DG_T1	Involve users in design in appropriate and familiar environments • The location should hold an appropriate social status • The choice of location should take into account the deficits of the participants and ensure easy access to the meeting room • Using the person's home might help to make the participant feel at ease	[9][45][46][47]
DG_T2	Adapt the language to participants	[2][9][41][44][48][49]
DG_T3	As the verbal might be a problem, make use of non-verbal elements such as visual stimuli like photos of objects or physical artifacts (notes, etc.)	[9][50][51][52][53][54]
DG_T4	Use distinctive contextual cues (like nametags)	[4]
DG_T5	Consider the fidelity of the tools used to design • Consider using physical artifacts	[4]
DG_M1	Consider activities that facilitate challenges in envisioning future solutions • Boost sharing personal experiences [9][41][44][46][55][56] • Support the building of IT literacy [57] • Provide more hands-on activities and collective prototyping [55][58][59] • Use visual cues [41][42][55][59] • Make use of fictional characters in different scenarios [60] • Try to avoid appealing to the person fantasy; avoid too much choice [9]	[2][9][42][44][48][54]
DG_M2	Consider activities that facilitate challenges with abstract concepts • Explain technological concepts in an easy-to-understand way [41] • Consider the fear of sketching [61] abstract ideas • Let the designer do the sketches if needed as a start for discussion [62]	[41][50] [59]
DG_M3	Involve people in designing valuable solutions, real purpose, interesting	[9][44][63]
DG_M4	Plan activities to surpass challenges in continuity • Using a document design history or summary documents of each session	[41][43][51][64]
DG_M5	Use previously known activities and natural tasks	[9][55][59]
DG_M6	For each activity create a relatively open artifact and brief	[48]
DG_M7	Provide alternative activities so to engage all participants • Adapt methods so that it will take into account the difficulties in the comprehension and production of language, both verbal and textual • Adapt methods so that it can overcome impairments of memory • Facilitate participants to stay on track based on their individual needs	[9][48][50][65][66]

No.	Guidelines	Reference
	• If working in a group, modify the method considering the different impairments each member of the group is facing • Consider the possibility of organizing individual participatory design sessions • Consider personalization and individuality for each patient	
DG_M8	Consider activities that can be flexible and empathic to adapt to the needs of the group: • Activities that can help create a friendly environment [44][46][67] • Activities that can boost participants self-esteem and confidence [52][68] • Activities that can include elements of playfulness [42][52][55]	[9][42][49][50][54]
DG_F1	Researchers should clearly explain the purpose of events and the role of the participants	[9]
DG_F2	To enclose personal info from the facilitators will boost participants confidence and make it easier to share things	[9][69]
DG_F3	Incorporate Structure and Review in activities • It is important to foresee enough time for participants to get to know each other, repetition and constant reviewing of the different research/design phases	[2][9][43][46][54][59]
DG_F4	During a participatory design session, try to minimize distraction and keep participants on focus	[9]
DG_P1	Consider a one to one or group work in a PD session • Try to overcome the challenge of working in groups [70] • Try to diminish the risk of the designer strong position [45] • Try to overcome deficits by pairing persons with different deficits into one subgroup [9]	[9][54][71]
DG_P2	Carefully decide the session duration and number of participants • In people with dementia [9] suggests working in small groups	[2][9][46][52]
DG_P3	Involve caregivers as support in conversation with participants • Third-party involvement [56][59]	[2][9][41][51][59]
DG_P4	Involve caregivers as domain experts in the design process	[41][51] [72]
DG_P5	Eliminate usability problems with the carers of the patients • Specialist are relevant in generalizing solution [51] • Use persons who do not suffer from a deficit to get rid of general design problems [2][9]	[4][9]
DG_P6	Promote the involvement of family members; However, the involvement should be associated with a critical attitude	[73][74]
DG_A1	Try not to over-analyze the utterances of the participants	[9]
DG_A2	Be critical towards the representativeness of the participants	[9]

B. Participatory design with people with cognitive impairments

Research in PD with people with cognitive impairments is not novel. Researchers have been conducting PD with people with dementia, aphasia, amnesia, stroke patients, or in general, in older adults' populations, etc. for more than two decades. A set of workshops focused on people with cognitive impairment has been taking place in conferences [33][73][74][75]. Moreover, a considerable number of papers had been published [4][9][33][44][76]. The papers are mostly focused on describing and analyzing single PD projects and deriving implications for involving people with cognitive impairments in the participatory design process. Hendriks, Truyen, and Duval [9] present a broad review of conducting PD with people with Dementia and list a set of guidelines for participatory design together with persons with dementia. In their review, they have looked into PD projects with other user groups that have similar symptoms as persons with dementia such as amnesia, aphasia, and elderly. We build on their findings and expand them further with some findings from a literature review that we conducted in January-June 2019. The findings from the literature review are presented in Table 1.

As stated above, as a research question in this paper, we investigate what a researcher should take into consideration when conducting PD with people with MACIs. However, as mentioned above, the number of publications specifically related to this user group is low, and only a few other publications refer to PD with stroke patients. Hence, in order to have a broader overview of how to conduct a PD project with our user group, we did a systematic search in the literature of conducting PD with people with any kind of cognition challenges considering the similarity in symptoms.

We limited our search to the ACM and Springer databases since they are the main publishing venues for conferences and journals in design. We initially planned to investigate publications in specific conferences. However, in order to mitigate the risk of leaving out any relevant publication, we decided to expand the search generally for the two databases. We used several search terms in both databases. The constant search term was "participatory design" or "codesign" (and variations of it), qualified by more specific searches for user groups that experience cognitive impairments such as older adults, people with dementia, aphasia, cognitive decline, brain injury, and stroke.

Moreover, we added search terms that relate to the symptoms that people with cognitive impairments face, such as memory, attention, and tiredness. The search gave us an extensive set of papers. After removing duplicates, we ended up with 326 papers in ACM and 146 in Springer. The initial phase was to read through the abstract and quickly scan the papers' headings if there was any part that was dedicated to PD or the design process. Based on this, we decided if we needed to read the paper further. From the first scan, we decided to read 105 ACM papers and 38 Springer papers thoroughly.

After this, we discarded papers found to be out of scope. Some because they did not explain a specific case of participatory design with people facing some form of cognitive impairments, some for just mentioning a PD process without additional information, and somewhere the design process was not a true participatory design process with the involvement of users as partners in design. We concluded the selection with 105 papers. We classified the papers into Technology papers (18); Methods papers (49); PD practice papers (28) - in which the PD process and the tool developed were explained; and General PD challenges papers (17) - focused more in a conceptual discussion of what implications and what concepts are important on co-designing with people with disabilities. It was not a precise positioning of the papers in one of the categories mentioned above, and some could belong to all. However, each paper was assigned to only one category based on the paper's main contribution.

To analyze the data from the literature review, we were guided by content analysis and grounded theory approaches [77]. The content analysis starts by assigning specific descriptors to blocks of text in the collected data, a process called "coding". The coding can be emergent or a priori. The emergent coding is the core of the grounded theory approach, and the codes emerge from the data under review. Apriori coding involves the use of an established theory or hypothesis to guide the selection of codes. These categories might come from previously published work in related areas, or own prior investigations of the topic at hand.

We started by openly coding our data. Codes that described similar guidelines were grouped into concepts. Concepts were further grouped into categories (axial coding). Throughout the coding process, both authors of the paper were engaged in intensive discussions to find meaningful codes or concepts (i.e., topics).

To compare the results and refine and enrich our emergent codes, we used apriori coding in the second round of analysis. The apriori codes used derived from Hendriks, Truyen, and Duval [9]. Moreover, Hendriks, Truyen, and Duval [9] have categorized their guidelines. We preserve these categories and introduce a set of guidelines and actions to take for each guideline suggested by different authors (cross-checked with the guidelines from Hendriks, Truyen, and Duval [9]) for each of the categories.

In Table 1, we have listed guidelines for conducting PD with people with cognitive impairments, and group these guidelines into the following categories: Preparation (coded as DG_PP), Tools (coded as DG_T), Moderator (coded as DG_F where F stands for the facilitator, inspired by [78]), Methods (coded as DG_M – instead of methods we will refer to this category as Techniques inspired from the Simonsen, and Robertson [8]. We save the letter M in coding as the letter T has been used for the Tools category already) and Participants (coded as DG_P) and Analysis (coded as DG_A).

IV. METHODS

In this section, we initially present the data collection method, followed by the method used for analysis.

A. Data collection

The study aims to define a set of guidelines for conducting PD together with people with MACI. For defining the guidelines, we build on two empirical cases where we conducted PD with people with MACI.

In the first case, the aim was to redesign the Goal-Plan document used as a central document of patient rehabilitation at the DCR. The redesign aimed to make the document more useful for the patients during their rehabilitation.

Table 2. A summary of activities on how empirical data was collected

	Workshops	Participants	Recordings	Facilitators	Reflection-on-action	Preparation meetings
Workshop Outline 1	Workshop 1	4 patients	1h:10m	2	Facilitators + clinical representatives	3
Workshop Outline 2	Workshop 2 Workshop3	4 patients 2 patients	1h:10m	2 2	Facilitators + clinical representatives	2
Workshop Outline 3	Workshop 4 Workshop 5	2 patients + 3 staff 5 patients + 5 staff	1h:45m	2 2	Facilitators	2 2

We participated in the project as researchers pursuing our aim of investigating how to involve MACI patients in PD and designers to help the DCR to redesign the Goal-Plan.

Different methods and techniques can be applied in PD projects to involve the users in design. In the PD handbook, Brandt, Binder, and Sanders [30] describe a set of techniques that emphasize different parts such as telling, making, and enacting or the possible combination of these. We decided to involve MACI patients in PD workshops as our method of investigation. Workshops give the possibility to evaluate different traits of user involvement in the design, thus giving us the possibility to explore more on MACI patients and how to conduct PD with them. In a workshop, several techniques can be combined.

For redesigning the Goal-Plan project, we worked together with a project committee with representatives from the multidisciplinary team at the DCR. We prepared and conducted three workshops with a total of 10 participants. All three workshops were audio recorded. Moreover, after the workshops, a reflection meeting was conducted between facilitators and clinical representatives to discuss the workshop and the participants' engagement. The first author kept notes from these meetings electronically.

The second case is a continuation of the first case. The aim is to design a digital Goal-Plan that can be used by patients and staff in the process of defining rehabilitation goals and keeping track of the goals throughout the time that the patient is at the DCR. Thus, the digital tool would work as an enhancement or substitution of the current paper document. Two workshops with people with MACI, where a total of 7 patients and 7 multidisciplinary team members participated, were organized as part of the project.

The authors of this paper were involved in the project as researchers and designers. Both authors worked in the preparation of the workshops. The first author was as well a facilitator in the workshops. Both workshops for this digitalization of the Goal-Plan project were audio-recorded, and the reflections from the workshops were as well audio recorded. A summary of the data collection is presented in Table 2.

B. Analysis

To analyze the experience of conducting PD with people with MACI, we build on Schön's [79] approach of the reflective practitioner. Schön describes two types of reflections:

Reflection-in-action is undertaken in the indeterminate zones of practice. The reflective practitioner "*thinks up and tries out new actions intended to explore the newly observed phenomena, test tentative understandings of them, or affirm moves invented to change things for the better. What distinguishes reflection-in-action from other kinds of reflection is its immediate significance for action*." ([79, pp. 28-29]). Referred to as a reflective conversation with the situation.

Schön's use of the term reflection-on-action refers to the process of making sense of an action after it has occurred. It serves to extend one's knowledge base.

The two PD projects described in Sections V and VI have involved both reflections in action and reflection-on-action. Some reflections for the first case (Section V) have already been presented in a previous publication [1]. Those reflections were made before the literature review. The reflections presented in this paper have been refined further due to the findings in the literature review.

The analysis was conducted in two parts. Initially, for each of the cases, the authors, based on the experience of conducting PD with MACI patients, made a list of reflections on each of the workshops. The list of reflections for the three workshops in Case 1 started in June 2018 and was published in March 2019 [1]. However, we expanded the list of those reflections in January-February 2020, where additional elements of the workshops or the preparation phase were listed as reflections. For Case 2 and its two workshops, the list of reflections was made in February 2020. The reflections list is what Schön [79] defines as reflections-on action. The reflections on action presented in this paper are the ones from the perspective of the facilitator in the PD sessions and not through an evaluation of the sessions from the patients' perspective.

We present the reflections for each workshop outline because the same outline had mostly the same reflections. If there were different reflections among workshops in the same outline, we have made sure to capture and include it in the reflections by referring specifically to the workshop.

The second part of the analysis was the refining of the reflections drawn on existing literature guidelines for conducting PD with people with cognitive impairments. The initial reflections list for each workshop outline was put in an excel sheet where each reflection was inserted in a different column. Instead, in the rows, we listed the guidelines found in the literature (as in Table 1). Figure 1, the under excel sheet, shows this part of the analysis. We started a qualitative "correlation analysis" based on reflections and interpretations. We initially went through the guidelines from the literature and analyzed which of our reflections from the empirical cases were compatible with specific guidelines found in the literature. Some of the guidelines in Table 1. helped the authors reflect on topics we had taken for granted in the initial reflective analysis, leading to updates in our reflections' lists.

Moreover, a second round of reflective interpretative qualitative "correlation analysis" was undertaken. Again, we read through the guidelines from the literature and analyzed which of the reflections were compatible with them, leading to further refinements of the reflections list.

In the third round, we started grouping our list of reflections based on the categories that we had in the guidelines from the literature in Table 1. These categories are borrowed from Hendriks, Truyen, and Duval [9], and are Preparation, Tools, Techniques, Facilitators, Participants, Analysis. We present the reflections for each workshop outline divided into each of these categories.

In the fourth round of analysis, we created a new version of the excel file and created separate sheets for each of the categories, as shown in Figure 1, the top excel sheet. The reflective interpretative analysis in this phase led to a set of guidelines for conducting PD with MACI patients, emerging from the literature of PD guidelines with people with cognitive impairments and the experience of conducting PD with MACI patients in two projects.

The correlation analysis was also influenced by the characteristics of cognition challenges that the MACI patients have and the suggestions coming from rehabilitation theories, as described in the "Cognitive Rehabilitation Manual" [23]. The final list of guidelines for conducting PD with MACI patients is included in this paper's discussion.

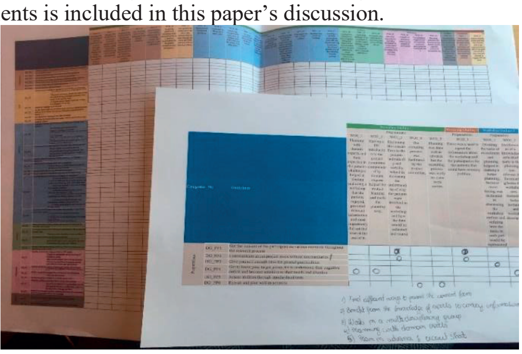

Figure 1. Visualization of the excel sheet used for the analysis and the smaller sheet of analysis for tools guidelines for conducting PD with MACI patients

V. CASE 1: REDESIGNING THE GOAL-PLAN

Above we presented the cognitive rehabilitation process in a hospital in Norway. The structure within the hospital, which is specialized in cognitive rehabilitation for patients with MACI, is the DCR. One of the primary working documents at the DCR, as explained above, is the Goal-Plan. Intending to empower the patient, the DCR wanted to redesign the layout of the document so it would fit more patients' needs and consequently make the patients make more and better use of the document during their stay at the hospital. We will refer to this project in this paper as "the redesign project".

As stated above, the authors were involved in the project in the role of researchers and designers to investigate patients' needs and, together with the patients, redesign a new version of the Goal-Plan that would fit those needs. Both authors worked in the preparation phase and the reflective analysis presented in this paper, and the first author participated and facilitated the workshops described below.

In collaboration with a project committee with representatives from the multidisciplinary team at the DCR, we prepared and conducted three workshops with the patients. The title of the workshops was: Redesign the Goal-Plan: A patient's perspective. The workshops aimed to get an understanding of what experience the patient has had with the Goal-Plan and discuss ideas on how to redesign that document so that patients can integrate it more in the activities during their rehabilitation period at the hospital.

In total, ten patients participated. In the first two workshops, patients that had been at the hospital for more than a week were invited, so they were familiar with the document to be redesigned. Four patients participated in the first two workshops. In the last workshop, only two patients participated, who were back at the hospital for their follow-up week, six months after their discharge. We were two facilitators – the first author in the role of facilitator and designer and as well one representative from the hospital who had an experience of working with this patient group but was not their direct therapist at the DCR. We refer to this second facilitator as a "knowledgeable third party" [1].

Below we describe the preparation process for the workshops and present and reflect on two workshop outlines

A. Preparation

In the preparation phase, we collaborated with a multidisciplinary team at the DCR. This team was assigned as a leading committee for the project, and we refer to it in another publication as the multidisciplinary project committee.

The committee was compounded by therapists who had high expertise in working with MACI patients. We refer to these people as "domain experts".

In order to facilitate the collaboration in the planning phase, prior to workshop 1, the first author conducted a PD workshop with the multidisciplinary project committee. The aim was to introduce the committee to some of the techniques used in PD and also for the first author in the role of researcher and designer to learn more about the user group. The workshop was initially seen with skepticism from the committee members, but once they understood the aim, they expressed that it was useful to learn about the PD approach and be able to contribute to *"design"* better workshops to enhance MACI patients' engagement.

Based on an agreement with the project committee and some shared editing iteration, the DCR staff members gave patients before the workshop a consent form, including an invitation to the workshop and a description of the project. The consent form was written in a very simple language to make it easier for the patient to follow. However, it was a detailed and consequently long description, to make sure that all the ethical issues were covered.

The project committee members tried to recruit their patients, asking if they would be interested in participating in the project. The patients that showed interests were then presented with the project invitation and the consent form. We were aware that the description might be excessive for the patient and could make her/him neglect reading it carefully. To make sure that the patient understood the consent form, one of the staff members at DCR spent time with the patient (that had expressed the willingness to participate) before the workshop, going through the document, and provide further explanations where needed. The workshop time was included in the participant's weekly plan. This is a calendar document where all the activities of a patient at the hospital are listed. The participants said that listing the workshop in the calendar helped them remember.

Regarding ethical concerns, we decided together with the committee that no personal patient data would be recorded. However, the sessions would be audio recorded so we could analyze the data later. The data collected through recordings are considered not anonymous (they are identifiable data), so they would be stored carefully in a safe location. In accordance with the project agreement, all digital data was stored in a personalized folder at the hospital servers.

During the first workshop, we noticed that some patients did not have a clear idea of what they had committed and needed a reminder. Thus, before workshops 2 and 3 in the morning of the workshop day, the nurses at the DCR talked with the patients again, to make sure the patients understood the scope of the project and were reminded and more prepared for what they were participating in later in the day. This was especially useful for patients with memory problems.

Moreover, we decided to conduct the workshops in environments that were familiar for the patients at the unit and would be adequate not to distract the patient and influence in their attention.

B. Workshop Outline 1

We organized Workshop 1 in two parts.

The first part was "storytelling". The title was "Sharing your experience". We invited participants to talk about their experience with the Goal-Plan. Moreover, we provided participants a whiteboard with a print out of the old Goal-Plan was set in the middle and sticky notes in different colors. The patients could use those to write down keywords to facilitate remembering what they had to say when their turn would come.

In the second part, we challenged participants to think, "How would they want their Goal-Plan to look like" and design the idea afterward. The technique chosen was drawing and discussion.

For the second part, we removed the Goal-Plan and gave each of the participants a white sheet of paper, where they could design their ideal Goal-Plan.

The first author led the session. The second facilitator was facilitating the communication with the patient when that was needed.

C. Reflections-on-action

In this subsection, we present a set of reflections-on-action from workshop outline 1. Reflections are grouped based on the categories borrowed from Hendriks, Truyen, and Duval [9] and also used in Table 1 above. The reflections are presented as insights on best practices or problems we faced based on a look back on our experience while conducting PD with MACI patients. We refer to these reflections again in the discussion section when we analyze these reflections from a theoretical perspective and conclude with a set of guidelines for conducting PD with MACI patients. Numbering the reflections has no specific meaning, but it useful to refer to after in the discussion.

Preparation

- WO1_1 – Involving domain experts in planning the PD process for the MACI patients resulted in arranging a workshop which was enjoyable for the participants and provided the researchers with relevant information. Moreover, for a researcher or designer would be very difficult to gain deep knowledge of the patients' needs in the timeframe of a project. Thus, having in the planning team, the domain experts facilitates having a broader perspective for the patient group and planning better.
- WO1_2 – Having a PD introduction to the project committee compounded by domain experts helped the mutual learning and made the planning easy. We, as designers and researchers, learned more about the user group, their needs, and challenges. During the mutual learning period, the first author had in situ conversations with the domain experts about the patients and how to design with MACI patients. Relevant tips and literature were exchanged in the conversation. Moreover, the domain experts gained new knowledge about the PD techniques and gave more specific recommendations on the activities that could be adequate or not for the workshop participants.
- WO1_3 – Explaining the consent form individually and verbally to the patients that had shown interest to participate in the workshop helped in increasing their understanding of the workshop's aim and how the data would be collected and stored. The lack of a verbal explanation would have caused one of the participants not to understand what was signing for. The person was diagnosed with dyslexia.
- WO1_4 – The project committee facilitated the recruiting process. The patients were already in the hospital unit, so it was easier to invite them to participate. However, in order to establish a relationship with the hospital and receive permission to conduct research in the DCR, it was a long process. In this process, we had two significant gatekeepers that supported us.
- WO1_5 – Planning was done well in advance, but the recruiting process was mostly done on a one week before notice. This because the persons invited were at the hospital, which was easily accessible for the authors. However, the process was limited in time because the persons would be patients at the hospital only for five weeks. Moreover, the domain experts suggested that even if recruited well in advance there is a risk that the patient might forget about the workshop date or in another scenario, the change in his/her condition from one week to another can influence them to drop the participation (some can feel too tired, not motivated, etc.).

Tools

- WO1_6 – Involving the DCR patients in a workshop at the hospital, which was a familiar environment for the patients, created an easy-going atmosphere. We used a room the patients had been in before for some of the activities at the hospital. Moreover, the room was easily accessible to everyone.
- WO1_7 – We distributed the materials on the table. The participants liked to look through these carelessly distributed workshop materials on the table, but they did not use any of them. Any of the four participants did not embrace the unstructured and open way of presenting materials.

Techniques

- WO1_8 – The participants did not use the sticky notes at all in the first part. They instead expressed themselves verbally and shared their stories easily with the others—three of the participants engaged in talking about their stories and their Goal-Plan in the first part. Instead, writing down in sticky notes, the main points in their story was difficult, and the participants seemed uncomfortable to do. Thus, the facilitators dropped the idea and instead investigated more through in situ questions. One of the participants was more reluctant to share his stories. After the workshop, we found that the participant's cognitive impairments had influenced his ability to articulate himself.

- WO1_9 – The fear of white paper, the blank page syndrome [31][32], was made visible in the second half of the workshop. The participants were good at articulating their needs verbally, but they were not able to create a visual image of their needs and consequently design ideas. Participants received the white paper and felt uncomfortable to write something on it. Instead, they started telling the facilitators what they wanted to have in a new version of the Goal-Plan. Both facilitators, ones noticing the hesitation, immediately reacted and suggested the participants to not focus on the white paper but more telling us their ideas about a new Goal-Plan. All the participants received the white paper with them, and only one of the participants came back the next day with a design suggestion and talked personally to the first author. Joyce [33], in her dissertation, discusses the role of open options in creativity and finds how the openness of the design space can constrain creativity. That is what we experienced with the MACI patients.
- WO1_10 – Realizing the hesitation on writing in the sticky notes and designing on the white paper, both facilitators abandoned the writing and drawing idea and started bringing up the questions of the workshop as discussion points to elicit ideas and needs from the patients. This flexibility toward the participants' needs and comfortability made it possible to end the workshop with some interesting data from the participants and, most importantly, have an enjoyable session for the participants, which expressed the enjoyment to the facilitators.
- WO1_11 – The broad approach of the workshop was distracting for the participants. Opening the workshop by asking the participants to talk about their experience with the Goal-Plan resulted problematic. It made them focus more on their goals and their specific problems rather than the main project aim, the Goal-Plan layout. Noticing the distracting reaction that the initial more general questions about the Goal-Plan created, the facilitators started asking the participants more specifically about the Goal-Plan layout. This resulted in participants being more focused on the main aim of the workshop and giving feedback specifically for the issue at hand. In the planning phase, the domain experts warned facilitators about the patients' willingness to tell their story and the possibility of getting distracted and get lost in detail. We experienced this with our participants. The presence of the second facilitator contributed in improving the communication and bringing the participants in focus.
- WO1_12 – The participants had different MACI, which meant they had different cognitive challenges. This required that within the aim of the workshop to adapt to each of the participants' cognitive needs. We noticed that two of the participants were more focused on discussing personal goals than contributing to the layout of the document. Thus, to them, we started asking more specific questions with short, clear sentences. Instead, one participant was more reluctant to share his stories. Thus, we tried to ask indirect questions so the participant could start sharing some ideas, and also, we were careful not to push the participant out of the comfort zone.
- WO1_13 – The aim of the project concerned the participants directly. Thus, they were interested in contributing as much as possible. One of them expressed that the contribution to designing a new Goal-Plan would help maybe not them directly but others after them in their rehabilitation. The same participant had discussed the workshop in the evening with the kin, and they had together designed something in the white paper.
- WO1_14 – Building on the participants' personal experience and opinion resulted in being a positive experience because the participants where used at the hospital to share their stories with different therapists. Moreover, talking about the Goal-Plan from their experience created an environment that was friendly and boosted the participants' self-esteem as there was no right or wrong answer.
- WO1_15 – A thorough review of the literature about the patients' clinical condition as well as observing the patients in the unit, made clear that it is a very special user group. The committee suggested focusing on the patients' abilities and how to strengthen those abilities during the workshops. The staff highlighted the patients' willingness to share their stories and express themselves both through words and as visual imagery.
- WO1_16 – Based on the committee expertise, the optimal workshop duration would be 1 hour, divided into two parts, each of 20-30 minutes with a 5-10-minute break in between. In this way, it would be possible to have the patient concentrated all the time without fatiguing him/her. This was the case during the first workshop. The activities in each part lasted enough to not be overwhelming for the participants. The participants seemed happy after the workshop.
- WO1_17 – Creating a friendly environment with coffee and biscuits and long breaks was stated as a positive trait of the workshop from the participants. The had the possibility to talk more with each other and with the facilitators during the break. However, the participants knew each other from before as they had been involved in group therapies. This created a friendly relationship between them and, from our interpretation, influence positively during the workshop by boosting the participants' willingness to share their opinions and experiences.

Facilitators

- WO1_18 – Having as a facilitator, a "knowledgeable third party" improved the communication process for those participants whose communication ability was affected by brain injury. Discussing the issue of facilitators with members of the committee, we considered an extension of the workshop team by someone from the clinical side that knows how to work with the patient group but is not directly involved with the participating patients. The committee suggested a member from the Learning and Mastering Center at the hospital, which was specialized in providing patients with a deeper insight regarding their health. The member might have met the patients during other activities around the hospital but was not part of the DCR staff and not directly involved with the patients. The involvement of a person that fulfills this requirement as a facilitator in the workshop was very useful in smoothing the communication and boosting the participants' contribution.

- WO1_19 – Facilitator's challenges of not being fluent in the Norwegian language created a fun atmosphere that helped the participants to feel at ease and not be shy to highlight their challenges. Moreover, as a facilitator keeping up with a positive and humble attitude helped the facilitators to communicate with the participants better. Facilitators were speaking on a slow tempo and not in a feeling of rush. Moreover, facilitators used a simple language and showed respect for the participants' knowledge and experience with their situation.
- WO1_20 – The broad approach of the workshop diminished the direct participants' contribution to the design of the Goal-Plan document. Thus, the facilitators had to intervene to help the participants get back on track and focus them on the aim of the workshop.

Participants

- WO1_21 – The number of facilitators should balance the number of participants. We decided that two facilitators (the first author having design skills and the knowledgeable third-party having domain knowledge) would be sufficient in a workshop with four participants. This saved the balance during the workshop. The participants were in the majority, so they were not put in the spotlight, which could have created stress. However, having one leading facilitator helped to keep the focus in one direction.
- WO1_22 – The committee suggested that the maximum number of participants per workshop should be around 4 or 5. In this way, the participants would feel more comfortable and have the right space to share their stories and opinions. Indeed, that worked well in workshop 1 with the four participants. Each of the participants had a dedicated time to express her/himself.
- WO1_23 - Recruiting MACI patients at the hospital through domain experts made the process of recruitment easy. Moreover, the domain experts served as the gatekeepers for involving in the workshops MACI patients based on the standardized tests that the patient has had at the hospital.

Analysis

- WO1_24 – We conducted a reflective analysis with the two facilitators and representatives from the DCR. Analyzing the findings in an interdisciplinary group helped in making a better sense of the participants' behavior during the workshop (reflected in this paper) and their feedback (integrated into the new Goal-Plan design). The assessment of the participants at the hospital and knowing their diagnosis was useful in triangulating the findings and make out meaning from them.

After the first workshop with workshop outline 1, we reflected on the things that did not work perfectly during the workshop, and we made another plan for the next workshop. This leads us to workshop outline 2.

D. Workshop Outline 2

The workshop was organized as an updated version of a future workshop, as presented by Jungk and Müllert [80]. Future workshops have been widely used in PD. The aim is to make people critically discuss a current situation and then envision possible improvements for the issues critiqued in a fantasy phase. After a phase of envisioning any solution, it comes to the realization phase. In the realization phase, feasible solutions based on what the technology allows are discussed further. We ideated an updated version of the future workshop, as presented below.

The workshop was divided into three parts.

In the first part, the participants got a version of the old Goal-Plan printed out. Next, to each of the fields in the document, we added two icons, thumb up and down. We asked the participants to mark with thumb up those fields that they considered important for their rehabilitation. After choosing to thumb up or down, the participants were asked to share their choices with the others and tell a little bit why they decided so. The aim was that the participants could discuss the choices among each other and maybe build on the ideas of each other. To structure the discussion, the knowledgeable third-party facilitator started going from one field to another and asking participants for their choice. Thus, it made it easier for the participants to follow and contribute to the discussion.

In the second part, the participants were asked to try to rewrite the fields (words used in the document) that they found important, in a way that they thought would be easier to understand and read. The participants were suggested to add additional fields if they thought they would be important in the Goal-Plan. Again, they had to work initially on their own and then present their suggestions to others. The other participants could ask questions or comment. The facilitators asked questions to enable the participants to articulate more of their needs and sometimes ask questions to understand better what the participant meant, to not risk misinterpretation during analysis.

The third part was called "rearrange". In this part, the participants were asked to rearrange the fields of the document which they had selected and rewritten in the first two parts. They could arrange the document as they wanted, add new fields or, change the structure of the document. At this point, participants could use the template of the old Goal-Plan or get a white sheet and design on it individually. Colored sticky notes and pens were provided.

In the third part, the participants were also provided with some examples of designs made by the multidisciplinary project committee in the workshop with the designer. Participants could have a look at those sketches for a short period for inspiration. This exemplars' aim was to help participants surpass the white page syndrome.

The same workshop format was used in the third workshop, where two patients that came back for a follow-up week participated. The only change was that in order to customize the discussion for these two participants and adapt to their experience, we focused mostly during the workshop on how the continuity of the rehabilitation plan could be achieved when the patient leaves the hospital.

E. *Reflections-on-action*

In this subsection, we present a set of reflections-on-action from workshop outline 2. Reflections are grouped based on the categories borrowed from Hendriks, Truyen, and Duval [9] and also used in Table 1 above. Here we do not have any reflections in the category "Analysis", so this category is not included below. The reflections are presented as insights on best practices or problems we faced based on a look back on our experience while doing workshops 2 and 3 with MACI patients. Here we include only reflections that were additional in workshop outline 2. The reflections from workshop outline 1 had already been taken into consideration before planning workshop outline 2.

Preparation

- WO2_1 – In workshop 2, we found that repeating the information about the workshop and the participation for the patients that had committed to participate and were suffering from memory problems resulted in them being more focused during the workshop and more prepared on what they were going to discuss. The nurse, as in workshop 1, had a meeting with the prospective participants to help them understand the consent form. In addition, the nurse talked again with the patients in the morning before the workshop to remind them about the workshop. This brought a more engaged and wider feedback from the participants during the workshops.

Tools

- WO2_2 – Distributing the sticky notes and the colored pens in an organized way in each of the parts of the workshop was noted to stimulate the participants to engage with the tools. They did not have the hesitation to chose among the tools because they had a structured set of tools for each part of the workshop.
- WO2_3 – Having the Goal-Plan in a printed version in front of each of the participants individually as part of the workshop toolkit, helped them be more engaged with it. Participants could customize the printed piece of paper as they wished – they owned it. Moreover, using the workshop tools to collect data facilitated the interpretations. For example, we could count how many thumbs up or down were related to a field in the Goal-Plan.

Techniques

- WO2_4 – We implemented a task-oriented approach in the workshop. Each of the parts was framed as a clear task that would serve a specific purpose. Participants liked this approach. They engaged in significant discussions with each other and the facilitators. Moreover, they started building on the ideas of each other. If someone brought up a new idea that would also trigger a discussion among other participants.
- WO2_5 – We observed aiding the participants through specific cues such as marking thumb up and thumb down in the Goal-Plan, made it easier for them to starts the discussion and elicit their ideas. The usage of thumbs up and down was associated with more personal stories and individual opinions about why a specific field in the document was relevant or not. So, having a structured way where to start the discussion was useful in helping the patients to build up ideas and relate those to personal experiences. The cues included in the tasks facilitated participants' ideas and discussion. This created the opportunity for the facilitators to ask more questions to elucidate the meaning of participants' ideas.
- WO2_6 – Having a narrower scope of the PD session helped participants to stay focused and contribute significantly. While these reflections are not new, they appear very important in the case of patients with MACI.
- WO2_7 – In the critique phase of the future workshop, we did not organize a real critique session. Instated, we asked what the participants liked and what the participants thought needed to be improved further in the current Goal-Plan. Providing both the thumb up and down options enabled the patient to think that some things need to be improved, but at the same time, that there are other things that are extremely relevant and need to be preserved. This was useful to keep participants' good feelings and not expose them toward a negative mindset. Thus, considering ways of using positive rhetoric that can elucidate a critical perspective from the MACI patients in workshops is very relevant.
- WO2_8 – The second part of the future workshop is the fantasy phase. It was clear from the first workshop that the MACI patients could not produce much information while moving directly to the fantasy phase (hesitation of the white paper). Thus, before jumping to the fantasy phase, we introduced a transition phase by asking participants to rewrite some of the fields in the Goal-Plan that they thought could have been written better for them. Rewriting aided participants to start envisioning a better solution for the Goal-Plan but still be connected to the things that they knew, meaning to the Goal-Plan that they had seen many times. In another publication [1], we refer to this as "the teaser of future envisioning". The teaser is a simple known task that helped participants in transitioning toward the fantasy phase of the workshop and be able to design a new version of the Goal-Plan either by rearranging the old one or by designing in a white paper. The white paper syndrome was defeated, and participants could come up with design suggestions for a new version of the Goal-Plan. Figure 2 shows some of these design suggestions provided by patients.

- WO2_9 – The use of exemplars in the "rearrange" part of the workshop, might lead and influence participants' ideas. We were skeptical about the usage of these exemplars, but we wanted to observe what their influence could be and how the patients would react toward that. However, screening participants' designs did not reveal a noticeable influence from the exemplars presented. Based on our reflective analysis the reason the exemplars did not influence the design ideas was that they were presented to participants in the last part of the workshop, and participants had already built up a mental vision of their Goal-Plan in the previous phases. Moreover, we exposed the exemplars only for a short period and explained that they were supposed to be triggers for possible options of how a Goal-Plan could look like. Integrating exemplars was inspired by research through design and Gaver's work with the ludic design [81][82][83]. Looking at the amateur designs from the staff inspired MACI patients participating in the workshops to get the colored pens and sticky notes, and start designing, overcoming the fear of the white paper. However, this is a very delicate usage, and more investigation is needed.

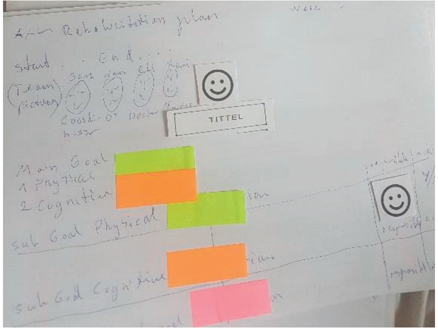

Figure 2. Workshop 2 - Patient's design suggestion

Facilitators

- WO2_10 – Providing structure and review helped participants to give more ideas and articulate their thoughts more deeply. The knowledge third party going from one field of the Goal-Plan to another to ask if the participants had marked that with thumb up and down facilitated the initiation of the discussion among participants. Moreover, asking additional questions helped participants to express their ideas better.

Participants

- WO2_11 – In the third workshop, the two participants were of different natures. One of them was more expressive, and the other more reserved. Hence, the facilitator had to make sure that both were getting the same time and attention by providing the same time and attention to both participants.
- WO2_12 – Participants with different backgrounds but similar cognition levels seemed to work better with each other. This was noticed, especially in workshop 2. The four participants had different MACI but more or less similar functional level. This helped in keeping up at the same speed and feeling motivated by each other.
- WO2_13 – We noticed that participants were comfortable with the group work. They were used in working in groups, from previous group therapies at the hospital. Many showed during the workshop confidence point to another patient on things they thought were similar. Moreover, we noticed that some participants who had different ideas from the group felt confident enough to share them with others. Especially if the idea they had was related to a story in their life. However, the situation was different in workshop 3 when one of the participants was perceived as influencing the ideas of the other. Facilitators had to intervene through more strategic questions to retrieved more hidden ideas. A helpful thing was that each of the participants had to work initially on their own and then discuss with the others in the group in its own turn. This helped in preserving the individuality of opinions.
- WO2_14 – Participants that were present in workshops 2 and 3 had a milder ACI (acquired cognitive impairments). Thus, they could contribute better in giving feedback on design details as well.

VI. CASE 2: DESIGNING A DIGITAL GOAL-PLAN

In June 2019, as a joint collaboration among our research institution and the DCR of the rehabilitation hospital, we started "The interactive Goal-Plan" project. The project aims to develop a digital version of the Goal-Plan, which can support the patients to take more control over their rehabilitation at the hospital and outside it. We will refer to this project in this paper as "the digitalization project".

Figure 3. Participants working in pairs patient-therapist during workshop 5

The aim of supporting the patient to take more control over her/his rehabilitation starts with the patients deciding themselves what they would like to have in a technological tool designed for them. This philosophy of the hospital is compatible with the PD principles. Thus, a PD process started in January 2020, where the authors of this paper in the role of researcher and designers were involved in two PD workshops organized respectively 22nd of January and 5th of February 2020 at the rehabilitation hospital premises with patients with MACIs and staff from the DCR. These workshops will be described below.

A. Preparation

In this project, a multidisciplinary project committee was created again. The first author in the role of the designer and researcher worked in close collaboration with few representatives from the DCR. One member of the DCR, which was involved directly with the patients, was in charge of the recruitment and deciding on a venue and time suitable for all. The planning of the workshops was done in collaboration among the authors of this paper and an Occupational Therapist (OT) that had been working at the DCR before but was now in other duties at the hospital. This person had been a crucial person in the first case described above. Thus, she had created knowledge about the design process and the PD principles previously. As she was not directly involved with the patients but had high expertise in working with the patients, she represented the "knowledgeable third party" in this project. A more elaborate plan was made considering the experience of the facilitators and the lessons learned from the first case.

For workshop 4, the plan was to recruit 5 patients. However, only two patients responded positively to the invitation. The workshop was planned to have a room that could support groups working in pairs, but the room available had only one single long table. We needed to be flexible to the positioning of the participants, so not much noise was created and distract the patients. Workshop 5 was planned for the 29th of January, but we needed to postpone it due to a small number of patients willing to participate. Workshop 5 was organized in a room called the "Idea Lab" suitable for bigger group workshops.

Participants in this case workshops were patients and DCR staff members. Hence, we prepared two invitations and consent forms in order to make the call more personalized. The consent forms this time were shorter and more precise. It had a clear part highlighted in colors where the aim of the workshop and each of its parts were presented. This was followed by a description of how the data collected would be handled. The one-page invitation resulted in being easier for the patients to read through and understand. The "knowledgeable third party" mentioned above contributed substantially to writing the consent form. Moreover, together with the designer (first author), they drafted the workshop description and presentation. The presentation was planned to stay on the screen, and the written material was distributed to the participants as a cue for understanding better the tasks in each of the parts.

B. Workshop Outline 3

In workshop 4, two patients and three therapists from the DCR participated. The workshop was called "My Interactive Goal-Plan – Defining goals", and the aim was to envision and discuss requirements for a digital tool that can support the patients to be more involved in setting their rehabilitation goals during their first week at the hospital. The workshop was planned to have three parts. The duration of the workshop was planned for 1.5 hours, with each part having 25 min and 10 min break between parts. We ended doing only the first two parts in 1.5 hours because more general preparations took time, such as sitting in the right place, explaining the tasks, and showing examples.

The first part consisted of a set of cue cards with possible functionalities for a digital Goal-Plan. Each of the patients' participants had a set of cue cards in different colors. The participants had to read the cue cards individually and chose among the set of cue cards, those cards that involved functionalities that they liked. There were no limitations in the number of cards to choose from. Participants were also given empty cards so they could add more functionalities if they wanted.

As a second task of the first part, participants were asked to choose the five most favorite cue cards. These five cards should be presented later to the other participants in the workshop. After presenting the five cards chosen to the other participants and telling them why the person thought the card was relevant, all participants had to discuss in the group and agree on a set of five cards that all thought were the most important functionalities to have in a digital Goal-Plan that could support them in defining their rehabilitation goals. In the workshop in parallel with the patients' table, we had a table of therapists (staff members) from the DCR doing the same tasks. The set of cue cards that they had was targeted to therapists needed and desired functionalities in a digital Goal-Plan that could support their work in facilitating patient's rehabilitation.

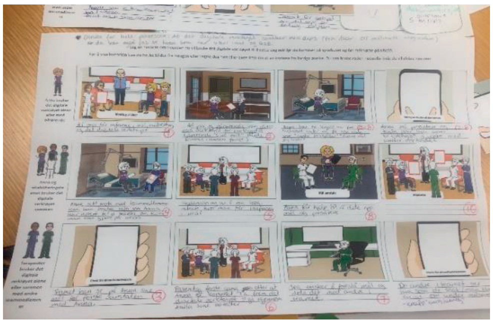

Figure 4. Storyboard created from one of the patient-therapist teams in workshop 5

The second part of the workshop required each of the patient participants to work in pairs with one from the therapists. The task the duo patient-therapist had was to make a story. The story would be on how the digital tool, which had the functionalities the patients and therapists had concluded in the first part as the most desirable ones, would be implemented in the processes at the DCR.

A paper storyboard was given to each of the pairs. The storyboard was divided into three parts to help the patient and the therapist to think about the activities the patient does alone, or activities the therapist does alone or activities they do together. A set of animated pictures picturing an animated fictional patient in specific moments at the hospital, home, or at the outpatient clinic was provided to the patient and the therapist as facilitating cues to make possible the creation of the storyboard. Facilitators told that if participants wanted, they could as well draw, or in case that they wanted to represent some functionalities of the digital tool, they could just paste in the storyboard one of the cue cards of the first session.

The last task was to provide the patient and staff with some choice of technology layouts such as phone, tablet, PC, and some cut out of possible icons and ask them to try to design the interface of the digital solution. However, the time spent in the first two parts did not create the opportunity for doing the last part, so we dropped the idea.

In the workshop, two facilitators participated - the first author and the "knowledgeable third party". Differently from the first case, the "knowledge third party" in this case was not only facilitating the communication but was as well in charge of leading specific sessions together with the first author - designer. The patient workshop was facilitated by the knowledge third party and the staff workshop by the first author. In the second part, each of the facilitators had to lead one of the pairs workshops, sitting on the two opposite corners of the table. We had one therapist more participating in the workshop. Hence, one of the therapists in the second part worked on the tasks alone in order to not shake the balance in the pair's groups.

Workshop 5 had the same outline. This time knowing the limitation in time, we scheduled only the first two parts of the workshop and gave time to other practicalities. The workshop was called "My Interactive Goal-Plan – Owning my rehabilitation". The workshop aimed to discuss how a digital tool can contribute to support the patient to be more in control and involved in her/his rehabilitation process after the patient has defined the goals. 5 patients and 5 therapists from the Sunnaas DCR participated. Two facilitators participated. A third person was involved in supporting materials distribution and making sure that everything was in place while the two facilitators were leading the sessions.

C. Reflections-on-action

In this subsection, we present a set of reflections-on-action from workshop outline 3. Reflections are grouped based on the categories borrowed from Hendriks, Truyen, and Duval [9] and also used in Table 1 above. The reflections are presented as insights on best practices or problems we faced based on a look back on our experience while conducting PD with MACI patients. Here we include only reflections that were additional in workshop outline 3. The reflections from workshop outline 1 and 2 have already been taken into consideration before planning workshop outline 3. The following reflections are focused only on the MACI patients. Even though the DCR staff members participated in the workshops together with the patients, their involvement in the process is out of the scope of this paper.

Preparation

- WO3_1 – Dividing the tasks of reDCRitment and planning as described above helped in doing better planning because more time was dedicated to discussing the workshop outline and refining how the tasks in each part would be represented. Moreover, the person in charge of reDCRiting had more time available to dedicate to explain to the patients that had expressed their will to join the workshop, the aim of the workshop, and why their participation would be relevant.
- WO3_2 – The involvement of a knowledgeable third party in the planning of the workshops was relevant for formulating better the workshop aim considering her expertise in the patients' group and the process of rehabilitation. Moreover, her engagement helped in formulating better invitation and workshop description that was suitable for the MACI patients and their challenges in communication.

Tools

- WO3_3 – Adding a written material given to participants during the workshop facilitated the information processing for them. Participants that had difficulties in understanding the requirements in each part of the workshop read what the task was about in the material written as a manual step by step with clear bullet points. The printed material helped them stay focused and have a higher level of understanding of the tasks.
- WO3_4 – Having short sentences and in a simple language suitable for the participants improved understanding and engagement. Moreover, the material was given in Norwegian. This helped the patient understanding and reduced the level of fatigue that speaking and reading on a foreign language can require.
- WO3_5 – Using low fidelity tools like the paper printouts in cue cards or in the animated images made it easier for the MACI patients to contribute to the workshop. The paper tools provided participants with the possibility to rewrite and move around based on their needs. Moreover, there was no fear that a card or a visual image was destroyed as we had a bunch of extra print outs ready to be distributed on needs.

Techniques

- WO3_6 – Cue cards facilitated the process of envisioning a future solution. The patient could agree or not with the hints mentioned in the cue cards. Sometimes an explanation of the cue cards information was needed. In that case, the facilitator would tell a little bit more on what was the aim behind those cards. Having initial cues helped to bring on participants' attention things that they might have forgotten on their own. Moreover, working on the cards and refining the ideas of the cards was expressed from the participants to be easier than having to initiate the thoughts themselves.
- WO3_7 – The openness of the cue cards gave the possibility to the patients to add their personal experiences. Some of the participants gave the cards other meanings based on their understanding and will. Thus, having cue cards not too detailed opened the opportunity for the participants to not just agree with the cues but be able to customize them, as shown in Figure 5.
- WO3_8 – Participants expressed that they found the project relevant and interesting for them and for other patients with MACIs in need or rehabilitation. This was

the main reason they had committed to participate. Moreover, as stated above, most MACI patients are still working, and they are familiar with the notion of workshops. One of the participants was working on service design and was very familiar with the techniques used.

- WO3_9 – During workshop four, considering the time spent on the previous tasks, both facilitators agreed to drop the third part of the workshop. After the workshop, both facilitators expressed that the participants needed a long time to read the cue cards and discussing them. This had created a delay in the previous tasks. Moreover, both facilitators noticed during the workshop, that the tempo of information processing was slower for some participants. Thus, providing them with the time they need is relevant to take into consideration.
- WO3_10 – In the second part of the workshops, we had created a fictional character for the storyboard. In both workshops, we saw that patients' participants were not influenced by this fictional character that we called "Anna". They quite often referred to this character as "me" – "I am the one in the story".
- WO3_11 – The second part of the workshop outline was more demanding than the first one. Participants had to discuss on the cue cards, make sense of them together (patient and therapist) and then make a story. These tasks put a high burden on cognition. However, the usage of the visual cues in the animated form facilitated the envisioning of the future solutions made more concrete in the case of the storyboard. The visual images enhanced creativity and sparked ideas for the story. Patient participants and therapists enjoyed having the visual cues and, as in the case of cue cards, took the freedom to interpret these visual images as they wished. Moreover, in this part, we introduced participants with an example of the storyboard created by the facilitators. Participants had the exemplar as inspiration and did not look at it in detail. However, the exemplar helped them envision what they had to do in the task.
- WO3_12 – Structuring the storyboard and how to build the story helped in making an abstract idea more concrete and the story more approachable for the participants, both patients, and therapists. The duo patient-therapist could divide the activities as instructed in the storyboard. Moreover, the structured way of creating the storyboard served for initiating a discussion on what activities the patients would like or should do alone and as well in which activities during their rehabilitation they can or should interact with the therapist. The structured way of thinking, and building the storyboard facilitated the patients' contribution to the workshop.

Facilitators

- WO3_13 – Coordinating 5 patient participants and 5 therapists as participants required more than two facilitators. In workshop 4, the facilitators had the possibility to sit with the therapist and the patient individually and try to ask in-situ questions when needed. Instead, in workshop 5, both facilitators were moving among groups but were not constantly present while the groups were working. Momentos, in which more investigative questions could have been asked, were lost. These were only realized afterward when hearing the recording.

Participants

- WO3_14 – One patient participant in workshop 4 was tired at the end of the workshop. Instead, all the 5 patient participants in workshop 5 stayed overtime and seemed to enjoy the tasks. From this, we want to highlight that MACI patients capacity variates, and in order to involve everyone and not risk tiring the participants, either participant with the same capacity should be grouped together in workshops, or we should design the workshop based on the capacity of the most fragile participant. This can be established before the workshop while knowing the participants' clinical condition.
- WO3_15 – The patients and the therapists participating in the workshops had a good collaboration. They both collaborated into making the story. Some patients initially struggled in the understating, but the respective therapists supported them by explaining the task so the patients could contribute significantly. The involvement of the staff members as participants in the workshop was not to ask them what the patients need in a digital Goal-Plan (the patients can speak for themselves) but to ask them about their share in the digital solution. Sitting a patient and a therapist together in designing a shared digital solution that will be used by them is not a common practice. Thus, in a future publication, we will expand more on how the collaboration in a PD workshop worked between these two user groups.

Analysis

- WO3_16 – Both facilitators conducted a fast round of reflections-on-action after each of the workshops. Facilitators discussed their individual and common impressions about the workshop and highlighted strong points and downsides in each of the sessions that they were in charge. This was audio recorded for future analysis and reflections. Those immediate reflections-on-action were very helpful in refining the list of reflections presented in this paper because the immediate reflections captured feelings and perceptions, which usually are lost when data is analyzed later in time.

VII. DISCUSSION

In this subsection, we discuss the findings from the reflective analysis from the literature review perspective. We conclude with a list of guidelines for working with people with MACIs for each of the categories initially introduced by Hendriks, Truyen, and Duval [9].

A. Preparation

In our experience, the preparation phase was conducted in close collaboration with domain experts. Thus, the experience that we describe is seen from the perspective of involving domain experts and people experienced with specific patient groups for planning the PD process. The literature recommends getting the consent of the participants at various moments throughout the research process [8]. Our participants did not participate for an extended period in the research. In our workshops, we experienced that the consent prior to the workshop was sufficient. Nevertheless, throughout the workshop, both facilitators were closely observing the participants for signs of fatigue or irritation and informally getting approval that the process was going well for each of the participants. An important insight from our study was the need to provide the information described in the invitation and consent form in different forms (verbal, visual, etc.) to the participants and repeat the informing process many times to ensure that the information is processed, and the person is aware of what s/he is committing to (WO1_3, WO2_1).

Another guideline from the literature is to communicate about the project goals without intermediaries [9] (DG_PP2). In our two cases, the domain experts communicated the project goal to prospective participants. Further, during the workshop, the facilitators repeated the project goal as a precaution to assure that all participants were aware about what they were contributing to. When the intermediaries are people that have knowledge about the cognition challenges of the patient group and are experienced and trained in communicating with them, the intermediaries can be an asset in establishing the communication with the prospect participants and explaining the project goals (WO1_3, WO2_1).

Moreover, in analogy to the literature (DG_PP3), we experienced that there was a need to establish an extra time for general practicalities [9]. However, this time could be managed better if the preparation phase was handled by a group of people who are part of the PD project. Dividing the recruiting and planning process among different persons created more space for ideating better the workshops in workshop outline 3 and as well manage better the recruiting process (WO3_1). The literature states that it is relevant to know the target group well [9][41][42] (DG_PP4), know the patients' deficits so you can adapt to their situation. For researchers and designers, a higher understanding of the MACI patients' cognition challenges can come due to the close collaboration with the domain experts – the rehabilitation specialists working with MACI patients in cognitive rehabilitation. They have deep knowledge about the patient group and can contribute to informing designers. However, PD requires mutual learning and applying this perspective to teach domain experts how designers work can help them provide more knowledge about the patient group (WO1_1). In our case, the selection of the participants was made through the clinic. Assessing abilities through standardized tests [9][4][43] (DG_PP5) was helpful in defining the patients' abilities and disabilities, and for us to plan adequately. They were also useful in the analysis. Ability assessment was not done by the designer but by the healthcare practitioners.

The literature states that it is beneficial to plan and reDCRit participants well in advance (DG_PP6). In the case of MACI patients, we experience that planning well in advance is recommended, especially when the designer leading the PD project is new to working with MACI patients and need to learn more about the patients' needs and situation from the healthcare practitioners. However, the reDCRiting process was done over a short period. This because patients do not stay at the hospital long, and some of them can forget about participation in the workshop if they were reDCRited well in advance. Moreover, patients' condition varies from one day to another (WO1_5). Thus, planning for absent patients is required.

In the preparation phase, we finalized these guidelines for conducting PD with MACI people:

1. Invite the patients and present the information regarding the project in different ways, either text, verbal explanations, images, audio, etc. and make sure to repeat the information several times during the workshops/activities based on the participants' needs.
2. Benefit from the knowledge of domain experts (in this case, the rehabilitation specialists) to recruit and convey the information about the project. They know how to work with MACI people.
3. Plan the PD workshops in collaboration with a multidisciplinary group. Establish mutual learning and make better preparation for the PD process by benefiting from the expertise of everyone.
4. Plan the project well in advance and recruit in a short time. Prepare for absences.

B. Tools

The literature emphasizes the need to involve users in design in appropriate and familiar environments, which take into consideration the deficits of the participants [9][45][46][47] (DG_T1). The same is true for MACI patients. The hospital environment was familiar, and the participants had previously been in the areas where the workshops took place (WO1_6). Moreover, these areas at the hospital are designed to offer easy accessibility for everyone. Another important element mentioned in the literature is to adapt the language to the participants (DG_T2). In the case of MACI patients, this is extremely relevant. Our reflections from the workshops (WO3_4) and existing literature [19][20] show the importance of using short sentences and an understandable language when addressing MACI patients.

Regarding tools used during workshops as supporting materials for techniques, we found that sometimes using text might be a problem, and it can be more useful to make use of non-verbal elements such as visual stimuli like photos of objects or use physical artifacts [9][50][51][52][53][54]. In our empirical data, we found that having the Goal-Plan in a printed version served as a stimulus for the participants (W02_3). Moreover, we experienced that MACI patients felt more motivated to use workshop tools if these tools were individualized. The MACI patients worked well in manipulating the tools provided initially individually and then sharing the outcome with others.

We did not use contextual cues such as nametags as it has been proposed in the literature [9] (DG_T4). This because the participants coming to the workshops knew each other from before.

In our experience, using low fidelity tools part of the workshop toolkit made it easier for the participants to contribute. However, we lack experience with digital toolkits, and further investigation of conducting PD building on digital toolkits is needed. Despite our lack of experience with digital toolkits, we argue that being aware and considering the fidelity of the toolkit [4] used in a PD project should be a priority. This should be carefully considered with regard to patients' abilities tested through standardized tests.

Finally, in WO1_7 and WO2_2, we highlight how the structuring of the tools became relevant for motivating participants' contributions to the workshops. This is compatible with the rehabilitation theories for building structure in remembering things and focus attention [25] and should be taken into consideration when presenting PD tools in workshops.

Regarding tools, we have the following guidelines for conducting PD with MACI people:

1. Involve users in a familiar environment
2. Use distinctive contextual cues in the toolkit materials
3. Consider the fidelity of the tools in relation to patient-specific cognitive challenges
4. Use a simple language with a positive tone
5. Use visual stimuli which are individually targeted
6. Have clear tools for each part of the workshop and have a structured way of delivering the tools.

C. Techniques

Having clear guidelines and techniques for conducting PD with MACI patients that involves a significantly heterogeneous group is difficult. Moreover, techniques can variate based on the technology to be designed. This may put other requirements in place. Here we highlighted insights from our experience within the two projects and five workshops, and we invite other researchers working with MACI patients to refine and supplement the list.

People with cognitive impairments find it challenging to envisioning future solutions [2][9][42][44][48][54]. In the literature, different ways of supporting the envisioning of future solutions are proposed (listed in DG_M1).

In our work with MACI patients, we have found that a task-oriented approach of activities (WO2_4) and narrow scoping of a session (WO2_6) can help the patient to process a line of information at once and to be able to envision more future usage of the solutions. The fear of using the white paper showed the challenge that MACI people have in envisioning a future solution and how the fantasy ability can be undermined when too many options are presented. Thus, as stated in the literature, trying to avoid appealing to the person fantasy and avoid too much choice [8] is adaptable for the MACI patients as well.

A relevant finding influencing the future envisioning is what we called the "teaser of future envisioning" (WO2_8) in the workshop outline 2. The aim is not to ask the participants directly to enter into a fantasy phase but use intermediary tasks that can aid the fantasy of the participants. In the literature is emphasized the relevance of making participants share personal experiences as a start for boosting future envisioning [9][41][44][46][55][56]. The teaser of future envisioning should build on personal experiences that make the participants think about the future.

Another important element for surpassing the challenge in envisioning future solution was the usage of cues in the form of written text cue cards (WO3_6) or cue cards with pictures (WO3_11). The usage of visual cues is recognized in the literature [41][42][55][59].

What we found interesting in our workshops was trying out the power of exemplars as a way to enhance creativity (WO2_9). The usage of examples of designs as a means to aid the fantasy of people with MACIs needs more consideration and further study. However, we can state that it was helpful for our participants who had different aspects of MACIs. It aided their creativity by making them think outside of the box. We observed that the exemplars presented in the form of amateur and not finished designs helped the participants relate more to them and feel more confident in designing themselves as they noticed that no finished and polished designs were expected by them.

In [9], using fictional characters has been defined as useful in envisioning future solutions. However, our participants seemed not to be keen on that. They wanted to be represented and talk about themselves instead of a fictional person. This is also related to rehabilitation theories where patients are motivated to accept and embrace their new selves.

In the literature, providing more hands-on activities and collective prototyping [55][58][59] is seen as contributing to participants' ability to envision a future solution. We experienced that for MACI patients, the envisioning process required a break down into smaller activities that could help the patient create a bigger picture by putting the pieces in each smaller activity together. This is similar to the memory rehabilitation theories [25], which suggest breaking down an activity in smaller steps and train each of the steps slowly, adding one step at the time. Using activities that are familiar is as well helpful to consider in techniques with MACI patients similarly to the findings from the literature [9][55][59].

Another challenge that people with cognitive impairments face is abstract concepts [41][50][59] (DG_M2). From our cases, we found that MACI patients also have a fear of sketching and the white paper syndrome, hesitating to draw. Based on this, designing more narrowed down (WO2_6) and structured activities (WO3_12) and tell personal stories or personal opinions (WO1_14) can help in surpassing the challenges of MACI patients with abstract concepts.

We also found that people with cognitive impairments are keener on getting involved in designing solutions that are interesting, valuable, and have a real purpose [9][44][63]. We have highlighted the same point in WO3_8 reflection.

Another element to consider in deciding about PD techniques to apply with MACI patients is to provide alternative activities that can support all the participants to engage [9][48][50][65][66] (DG_M7). With the MACI patients, we found that it is important to make an appeal to the individual participants' abilities (WO1_15). Moreover, alternative ways to present the tasks are needed, so it fits the patients' needs. MACI patients experience an increase in the time needed to perform activities. This is called the tempo of performing activities. Adapting to MACI patients' needs in the tempo of activities is very relevant for assuring that patients do not feel overwhelmed and rushed.

In DM_8 we found that it is relevant to consider activities that are flexible and empathic enough to adapt to the needs of the group, for example, activities that can help create a friendly environment [44][46][67], activities that can boost participants self-esteem and confidence [52][68], and activities that can include an element of playfulness [42][52][55]. We experienced that being flexible was required when working with MACI patients. Moreover, serving coffee and biscuits during the breaks helped to create a friendly environment. One of the patients made a video in workshop 5 and shared that with us to express his enthusiasm.

Regarding techniques, we have the following guidelines for conducting PD with MACI people:

1. Having a task-oriented approach where more complicated activities are presented in small steps that build on each other.
2. Having a narrowed scope for the PD sessions and not distracting people with MACIs with general questions.
3. Using cues that can support future envisioning. It is important to consider different ways of presenting the cues. Both text-based and images are useful. The cues should be open so they can offer the possibility for personal interpretations from the participants in the PD workshops.
4. Introduce in workshops “the teaser of future envisioning” and activity that builds on people with MACIs current experiences and ask them to think how these specific experiences can be improved in the future.
5. Take into consideration using exemplars that present examples of what the MACI people are expected to do.
6. Use positive rhetoric when asking for critical opinion. The aim is to not influence MACI people to enter in a negative mindset.
7. Prepare alternative activities that can include all the participants in the workshop independent of their disability.
8. Create a friendly environment by showing empathy and respect toward participants’ experience.
9. Involve MACI people in PD projects that are relevant and interesting for them.
10. Structure the activities as much as possible so it can be easier for the MACI people to conceptualize.
11. Try to avoid fictional characters in the design process. MACI people prefer to refer to themselves in the design.
12. Adapt to the MACI people's tempo while conducting activities in a PD session.
13. Be flexible to changes activities, drop activities, repeat the explanation of activities based on the needs, and the requirements of the MACI people involved in the PD session.

D. *Facilitators*

The literature emphasizes that one of the facilitators' responsibility is to explain clearly the purpose of the events and the role of the participants [9] (DG_F1). Similarly, this was important with the MACI patients were repeating the aim of the event in a clear language, and having it printed out during workshops 4 and 5 helped the participants stay focused and contribute significantly to the workshops. Moreover, the facilitator should try to appeal to the patients' challenges (WO_10) by highlighting that not everyone is perfect [9][69]. The MACI patients all come from a life without their current disability. Thus, making them feel good by emphasizing that the challenges are common among other people without the ABI can break the ice.

The literature also emphasizes that the facilitators should incorporate structure and review in activities [9][2][43][46][54][59] (DG_F3). They should give time to participants to know each other, have the possibility to repeat, and review parts of the workshops. With MACI patients, this was very relevant. The facilitator should also consider having a slower tempo to adapt to the patients' ability to process information.

Moreover, trying to minimize distraction and keep participants focused [9] (DG_F4) is also a challenging task when working with MACI patients. This can be supported by having more structured and narrowed down workshops where patients have short and clear tasks to perform.

One important finding from our work can be found in WO1_18, the involvement of the “knowledgeable third party” as a facilitator in the workshop. Considering the variations in MACIs, it would be impossible for a designer to be able to have the ability to communicate properly with every variation of cognitive impairment. A person that is specialized for working with MACI patients can support communication. Moreover, in the digitalization project, we saw the knowledgeable third party not only facilitating communication but also leading the PD sessions. This was the result of a long mutual learning process in which the designer and the knowledgeable third party had been involved throughout the “redesign” and “digitalization” projects described above. However, involving the knowledgeable third party and the number of facilitators in a session, in general, should be balanced to the number of participants in order to avoid putting MACI patients in the spotlight.

Regarding Facilitators, we have the following guidelines for conducting PD with MACI patients:

1. Involve a knowledgeable third party as a facilitator for facilitating communication and ultimately leading the sessions.
2. The facilitators should explain clearly the purpose of the events and the role of the participants for each part during the workshop.
3. The facilitators should incorporate a structure in the activities and the review of the activities.
4. The facilitators should enclose some personal information about themselves.
5. The number of facilitators should be balanced with the number of participants so the facilitators can devote more time to each of the participants or participants

groups and ask in-situ questions to uncover meaning in the ideas or provoke new ideas.

E. *Participants*

Using participant groups with few members is suggested in conducting PD with people with cognitive impairments [2][9][46][52]. This is also true for MACI patients. A number of 4-5 patients were suggested by the domain experts to be a good group size. The duration of the workshops should be short and adapted to the number of participants involved. Thus, enabling everyone to have a say and to not rush the slow tempo of some of the MACI patients. In DG_P1, the guideline is to consider one to one group work in PD sessions with people with cognitive impairments [9][54][71]. Moreover, Yaghoubzadeh, Kramer, Pitsch, and Kopp [70] state that cognitive impairments could be challenging for working in groups. From our reflections (W02_13), we found that participants had experience and worked well in a group. They were able to build on the ideas of others while still keeping their stand if they had a different opinion. The benefit of group work is also compatible with the rehabilitation theories, where group therapies are considered very effective [24][25][84]. However, we stated that not all MACI patients have the same abilities. When working in groups, it should be the facilitator's responsibility to give the same time, attention, and possibility to everyone.

Another guideline from the literature is to pair persons with different deficits into one subgroup [9]. This aims to surpass challenges in individual deficits by working as a group and contributing each with their abilities. In our experience, we noticed that participants who had different cognitive impairments, but the same functioning level could work better in the same group (W0_12).

The literature also recognizes the involvement of caregivers as support in conversation with participants [2][9][41][51][59]. In our case, we had direct caregivers as participants in the same workshop with the patients. Caregivers have usually been involved in the design process as patients' proxies for patients with some forms of cognitive impairments. MACI patients have the capacity to be involved and speak for themselves. Using caregivers as proxies is useful when the user group being represented in not able to be involved. In the MACI patients' this is not the case. In PD with MACI patients, domain experts can support the process of planning the work with patients and make sense of the patients' needs. Meanwhile, MACI patients can participate in PD activities.

In the digitalization project, an MACI patient and a therapist had to work together in making the storyboard. All seven pairs in both workshops 4 and 5 had a good collaboration. Thus, involving in a PD project as participants, both the MACI patients and the therapists in designing digital solutions can result in a positive experience.

Moreover, the literature discusses the elimination of usability problems with the carers of the patients [4][9] and using persons who do not suffer from a deficit to get rid of general design problems [2][9]. In our reflections, we found that the participants in workshop 2 with a milder ABI had the possibility to contribute more in design details.

The literature also highlights the need to involve the kin and the family in the design [73][74] (DG_P6). We have not experienced this in our cases. However, we want to argue that the involvement of the family members or kin should be done only when it is necessary, and the solution designed involves them as well. One of the patients in the workshop, when asked about family involvement, said: "I should decide if I should involve my family".

Regarding Participants, we have the following guidelines for conducting PD with MACI people:

1. Involve participants in group activities where they can work on their own and together with others.
2. Consider a small number of participants for a short period of time.
3. Involve a "knowledgeable third party" to support the conversation with the MACI participants.
4. Use persons with milder cognitive impairments for exploring design details.
5. Promote the involvement of family members as participants only in the design of the solution that involves them and when the MACI person agrees.

F. *Analysis*

Hendriks, Truyen, and Duval [9] suggest that the researcher should try not to over-analyze the utterance of the participants. Moreover, they suggest being critical to the representativeness of participants. These guidelines are also useful when designing with MACI patients. However, from our experience, we suggest that the reflexive analysis can benefit from the involvement of a team from different disciplines. This can also eliminate the problem of over-analyzing the utterance of the participants because a caregiver can take things less seriously than a designer that is new to the patient group.

Furthermore, implementing a structured reflection on the action right after the workshop where the facilitators reflect on the workshop in general, tools, techniques, participants, and their behavior can be very relevant to the analysis later because it captures the feelings at the moment, which often can pass undocumented.

Regarding Analysis, we have the following guidelines for conducting PD with MACI people:

1. Try not to over-analyze the utterance of the participants.
2. Have a critical attitude toward the representativeness of participants.
3. Involve people from different disciplines in the analysis, especially rehabilitation specialist in MACIs.
4. Incorporate a reflection-on-action structure among the facilitators right after the workshop.

VIII. CONCLUSION

In this paper, we present a set of guidelines for researchers and designers to conduct PD with people with MACIs. We have initially presented in Table 1 a summary of guidelines drawn from previous studies of conducting PD with people with cognitive impairments. Then, we have presented two PD projects that we conducted with MACI patients and presented a set of reflections from each of the workshop outlines we have been working with. The reflections have been further discussed in regard to the existing literature, and finally, a set of guidelines for conducting PD with MACI people has been introduced. While the guidelines are the final outcome of the paper, the rich description of the reflections-on-action is also a contribution to PD, which put emphasis on the situated knowledge generated in PD workshops. These rich descriptions in some cases are even more relevant to PD because they represent a story derived from the experience of the PD researcher that has conducted the study and highlight things that are usually overlooked on more formal guidelines. Hendriks, Slegers and Duysburgh [85] state that a good way to go forward on a codesign approach for people suffering from some form of impairments is "*facilitating researchers and designers to share experiences, best practices, lessons learned, and so on …in the form of method stories*"

People with MACIs compound a significant part of our society. This is increasing with the increase in the tempo of life. People are more in danger of accidents and consequently are at risk of having more accidental brain damage. In people with MACI in many cases, there are no physical impairments. MACI people work, go to school and try to live their life to the fullest. However, their daily life is challenging due to fatigue, memory problems, attention problems, loss of executive functioning, etc. Thus, they need to adapt their lifestyle to their new self and make use of aids to keep up with daily life activities. Technology can help in assisting MACI people.

In designing these new technologies for them, we need to involve the MACI people in design. They can significantly contribute to the design if the right means for enabling their contribution are provided. That is what we want to achieve with this paper.

We contribute by giving PD practitioners a list of guidelines for working with MACI people. Moreover, through these guidelines, we aim to make technologists turn attention to the MACI people and design more supportive technologies for them.

The number of participants involved in our study is small in comparison to the heterogeneity of the MACI people group. Our guidelines are not a final list, and we hope that more researchers will investigate on this user group and expand our lists. These guidelines are in the form of recommendation, and they should be combined based on the situation at hand, in which PD researchers and designers critically reflect on what can be adapted in their specific case and what not and what is the consequence in the PD process if one of the guidelines is not taken in consideration.

In the future, we will continue testing our guidelines in further projects with this user group. Additionally, we want to investigate how to involve more digital tools in designing together with MACI people and how we can involve in the best way possible the MACI people in the co-development of different types of digital tools meant for them, besides the cases presented in this paper. Furthermore, we want to investigate how much are the MACI people willing to participate in PD practices, and where do we, as researchers and designers draw the line.

ACKNOWLEDGMENTS

We are grateful to all those patients at Sunnaas rehabilitation hospital that participated in our workshops. Their participation made this publication possible. Moreover, we want to deeply thank all our partners at the hospital, specifically the Department of Cognitive Rehabilitation that worked with us in building the PD process and who share the same values as we do in terms of involving the patients in designing technologies or services meant for them. The activities of the case 2 presented in this paper were financed by the INTERREG Sverige-Norge project "VITAL - för den goda hälsan", under the grant number: 20202391.

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PAPER IV

ACHI19

Çarçani, K. and Holone, H. (2019). A Participatory Design “Method Story”: The Case of Patients Living With Mild Acquired Cognitive Impairments, ACHI 2019, The Twelfth International Conference on Advances in Computer-Human Interactions. ISBN 978-1-61208-686-6. pp. 210 - 217

A Participatory Design *"method story"*: The case of patients living with Mild Acquired Cognitive Impairments

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***Abstract* - This paper presents a story on how patients with mild acquired cognitive impairment(s) (MACI) could be actively involved in Participatory Design (PD) sessions. A detailed description of what mild acquired cognitive impairments entitles is given, followed by an overview of PD and how it might be relevant in the design of new ICT solutions for this user group. The story on how we applied the method is presented as a description and reflection by the authors involved in redesigning the layout of a document in a rehabilitation hospital. The paper aims to attract the attention of PD practitioners to the MACI user group and trigger discussion and questions about PD techniques for patients with MACI.**

Keywords: Participatory Design; Mild Acquired Cognitive Impairments; Method stories.

I. INTRODUCTION

There is an increase in chronic diseases in our ageing society and Information and communication technology (ICT) is seen as means to cope with the increasing number of these patients. A notable case are individuals with chronic illness affecting cognitive capacities. For this user group, ICT has become a fundamental part of *"their daily lives by providing a wide range of useful services and tools to use at home, work, or anywhere else"* [1]. However, an essential factor for the design of these new ICT solutions is the involvement of users in the design of those solutions that will be used by them in the future. User participation constitutes the core of participatory design [2], and that is what we will focus on, in this paper.

The user group in focus are people suffering from mild cognitive impairments after an acquired brain injury (ABI). The abbreviation "mild acquired cognitive impairment(s)" (MACI), coined from [1], will be used to refer to the user group further in the paper. Note that this is not an official abbreviation for the clinical condition.

Intensive research is ongoing regarding ICT support for patients with moderate or severe cognitive impairments [3-5]. However, less attention has been paid to patients with MACI and their needs, even though mild acquired cognitive impairments are a critical global public health problem and listed among the major causes of permanent impairments [6, 7],[8],[9]. MACI are usually described as invisible impairments and might include problems with memory, attention, executive functioning, language and fatigue. People suffering from MACI typically has a very challenging daily life, given the invisible nature of the condition.

This paper aims to first bring the attention of PD researchers and practitioners toward this category of patients, by sharing reflections from a participatory design research project conducted with this user group. Moreover, as Hendriks, Slegers [10] state, a good way to go forward on a codesign approach for people suffering from some form of impairments is "*facilitating researchers and designers to share experiences, best practices, lessons learned, and so on is considered very valuable*." [10]. This approach is alignment with Lee [11] in her paper "The true benefits of designing design methods". She suggests that the design field *"could reflect and re-specify its research direction for design methods, especially for empathic design methods, that is, not by developing new tools or pinning-down practices into recipes, but rather towards empowering designers to be more sensitive and comfortable with the design-led, local approaches that are essential to empathic design methods*"[11]. Thus, she suggests that designers should start presenting rich descriptions of *as it is* – what they actually did with methods in particular circumstances. She calls these descriptions *method stories*. Lee states that method stories help as a reflection tool for designers as the stories do not strip away the rich contextuality of actual use, including method application in and adaption to a specific context. In this paper we are not aiming to present a new method and give a clear formula of how to actively involve people with MACI in PD sessions. Instead we will share what Lee [11] calls a method story from a PD project with patients suffering from MACI. Thus, we will give a detailed description of a project that we did with patients with MACI and present some reflections and meta reflections related to that experience. The next section gives a more detailed overview of the user group, followed by a reflective section on why PD might be important for working with this user group. Further, we describe a project done with this user group in a rehabilitation hospital by the use of designer notes and methodological reflections [12], considering the reflections made before, during and after the workshops. The paper concludes with some meta reflections presented as design recommendation for applying PD with MACI patients.

II. MILD ACQUIRED COGNITIVE IMPAIRMENTS AND THE IMPLICATIONS IN PATIENT'S LIFE

In this subsection, we describe what it means to have mild cognitive impairments (MCI) after acquired brain injury (ABI).

Cognition is defined as the individual's capacity to acquire and use the information to adapt to environmental demands [13]. Based on Cicerone et al. [14] cognitive impairments may be seen in a) reduced efficiency, b) pace and c) persistence of functioning, d) decreased effectiveness in the performance of routine activities of daily living, and e) failure to adapt to novel or problematic situations. Cognitive impairments may be associated with cognitive decline due to normal ageing, more-serious decline as dementia, or can be the consequence of an acquired brain injury. The latest is the category of patients involved in this study.

ABI is brain damage acquired after birth. The causes of ABI can be "*from a traumatic brain injury (i.e. accidents, falls, assaults, etc.) and non-traumatic brain injury (i.e. stroke, brain tumours, infection, poisoning, hypoxia, ischemia, metabolic disorders or substance abuse)"* [15]. It can affect *cognitive*, physical, emotional, social or independent functioning. The consequences vary from mild to severe [16]. Thus, the spectrum of patients which have had an ABI is a mixed etiological group, based on the kind of acquired impairment and the severity of it.

The focus of this research is patients suffering from cognitive impairments after an ABI and with mild severity of symptoms. Eghdam, Scholl [1] and Nilsson, Bartfai [17] use the term mild acquired cognitive impairment for that category of patients. Eghdam, Scholl [1] states that "*MACI is a new term used to describe a subgroup of patients with mild cognitive impairment(s) (MCI) who are expected to reach a stable cognitive level over time. This patient group is generally young and have acquired MCI from a head injury or mild stroke*." In this paper, we borrow this terminology.

Cognitive impairments often persist after the ABI, and they can significantly affect an individual's abilities to perform everyday tasks, fulfil former roles and maintain personal-social relationships [17-19]. Thus, patient life becomes challenging based on the severity of their injury. Often the reported symptoms are not related to specific problems. Instead, it can be in the form of a headache, tiredness, irritation, anxiety and memory problems. The patient can experience difficulties in cognitive and emotional processing, while having no or limited movement disorders and being independent in self-care [17, 20].

[17] referring to the clinical definition of mild acquired cognitive impairment, in line *with the Mild Traumatic Brain Injury Committee of the Head Injury Special Interest Group and American Congress of Rehabilitation Medicine (ACRM)* presented in [21] lists these criteria for classifying a person with MACI. *:*

- *Minor motor dysfunction/no motor dysfunction*
- *Appear to function well in social situations occasionally requiring support*
- *May have some different cognitive disabilities, mostly within the area of attention, concentration and memory*
- *May have some concomitant emotional problems*

In this paper, we will use these four points as criteria for including participants in the research.

Treatment – Cognitive Rehabilitation

"*Cognitive rehabilitation can be defined as a learning experience aimed at either restoring impaired higher cerebral functioning or improving performance in "the real world" using substitution or compensation techniques*." [19]. Cognitive rehabilitation is offered in specialised rehabilitation institutions. The case presented in this paper relates to a project that we did with the Cognitive Unit of a rehabilitation hospital in Norway.

The hospital offers multidisciplinary rehabilitation to people with complex functional impairments following illness or injury. We focused only on the cognitive rehabilitation process. The rehabilitation at the hospital (inpatient) is carried forward by a multidisciplinary team which helps the patient to define realistic and attainable goals for improvement and then define, in collaboration with the patient, a treatment plan based on the predefined rehabilitation goals. This is called the "rehabilitation plan". The rehabilitation plan is imprinted in the "goal plan" document. This "goal plan" document is at the core of the rehabilitation process in the hospital. It coordinates the activities that both the patient and the multidisciplinary team get involved in during the patient's hospitalisation period. In every activity at the hospital both the multidisciplinary team and the patient should refer to the goal plan document. The patient continues with the rehabilitation plan at home and returns to the hospital after 2-6 months for short follow up and further adjustments of rehabilitation goals.

Now that an overview of the patient group symptoms and the rehabilitation process which he/she goes through (specifically the case of the rehabilitation hospital in Norway where we conducted our research), has been presented, we further give a description of PD and how that might be relevant for this user group.

III. PARTICIPATORY DESIGN

Participatory Design (PD) was established at the end of the 1970s with the aim to democratise both the working life and the design process of new information technologies [15]. PD emphasises the idea that, those who will be affected by the design of new information technologies or digital artefacts, should get involved and have a say during the design process of these technologies [22]. PD considers users as "domain experts" of the realities in which they live, so they must undertake the role of the designers [22].

In Routledge Handbook of Participatory Design, Simonsen and Robertson [2] define PD as:

"a process of investigating, understanding, reflecting upon, establishing, developing and supporting mutual learning participants in collective "reflection-in-action". The participants typically undertake the two principal roles of users and designers where the designer strives to learn the

realities of users' situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them."

At the core of PD is the idea of genuine participation in decision making. Genuine participation stands on a political rationale where the voice of marginalised groups is heard in the decision making that will influence them. Thus, designing technologies for patients with MACI require their participation in the design process. Their marginalised voices in a paternalistic healthcare system where the patient follows what the doctors says, should be raised and heard. By applying PD patients can have a say and genuinely participation in the design of new ICT solutions which will be used by these patients.

PD is applied as a set of general guidelines which should be adapted to the specifics of the project. Equalising power relations and democratised practices, two main principles of PD, arise due to the commitment that PD has in achieving genuine participation. Another important principle in PD is mutual learning. Mutual learning enables the establishment of a common understanding among different actors by finding common ways of working and exchanging knowledge and value [23]. Only through achieving mutual learning we can have achieve genuine participation.

In PD, a lot of research has been done regarding the active participation of people with disabilities in designing new technologies. Significant research has been done with dementia patients or specific severe clinical conditions affecting cognition (examples [10, 24-26]). Regarding the mild cognitive impairments, the focus is on old adults or people with intellectual disabilities. Little has been done with patients suffering from mild acquired cognitive impairments. Moreover, we are aware of only one paper which focus on the analysis and reflection on the techniques applied for active participation of patients suffering from mild cognitive impairments in design sessions [27].

However, as also stated in Hendriks, Slegers [10], researchers are adjusting common participatory design techniques to involve "fragile" groups in participatory design sessions with the designers and researchers. This requires new techniques and new participatory design guidelines to be considered and to emerge in the future. Moreover, as a conclusion in their workshop regarding doing PD with people with disabilities Hendriks, Slegers [10] suggest the sharing of designers' experiences through method stories [11] as the best way of moving forward in the crystallisation of design techniques suitable for people suffering from cognitive impairments. Hence, in this paper we will share the method story of our project, by giving a rich description of our activities.

However, in order to learn from our experience, we will take a reflective practitioner stand and present a set of reflections on our process.

In this paper we will use Schön's [28] approach of the reflective practitioner to present some of the reflections-in-action and reflection-on-action of how PD techniques could be applied in the case of patients suffering from MACI.

Reflection-in-action is undertaken in the indeterminate zones of practice. The reflective practitioner *thinks up and tries out new actions intended to explore the newly observed phenomena, test tentative understandings of them, or affirm moves invented to change things for the better. What distinguishes reflection-in-action from other kinds of reflection is its immediate significance for action*. ([28], pp. 28-29). This is also referred to as a reflective conversation with the situation.

Schön's use of the term reflection-on-action refers to the process of making sense of an action after it has occurred. It serves to extend one's knowledge base. We will use reflection-on-action in two layers in this paper, the reflections made after each workshop in order to prepare better for the next workshop and reflection-on-action with the whole project as the analytical perspective. We will use the term meta-reflections for the latest.

IV. PROJECT DESCRIPTION

Above we presented the cognitive rehabilitation process in a hospital in Norway. The structure within the hospital which is specialised on cognitive rehabilitation for patients with MACI is the Cognitive Unit (CU). One of the main working documents at the CU as explained above is the "goal plan" document. With the aim of empowering the patient the CU wanted to redesign the layout of the document so it would fit more patients' needs and consequently make the patients make more and a better use of the document during their stay at the hospital.

The authors were involved in the project in the role of researchers and designers to investigate patients' needs and together with the patients redesign a new version of the "goal plan" that would fit those needs. Both authors worked in the preparation phase and the reflective analysis presented in this paper and the first author participated and facilitated the workshops described below.

In collaboration with a project committee with representatives from the multidisciplinary team at the CU, we prepared and conducted three workshops with the patients. The title of the workshops was: Redesign the "goal plan": A patient's perspective. The workshops aim was to get an understanding of what experience the patient has had with the "goal plan" document and discuss ideas on how to redesign that document so that patients can integrate it more in the activities during their rehabilitation period at the hospital. As the document is given to the patient in a paper format, during the workshop we did not put any technological limitations, instead allowing the patient to be free to envision any solution.

A. Preparations

Designing the right workshop for people with mild cognitive impairments has specific challenges and require thorough preparation. To plan and prepare the workshops, we worked in close collaboration with a multidisciplinary team at the CU. The team was assigned as the leading committee for this project and will be referred hereafter as the multidisciplinary project committee. It consisted of the CU staff members of different professions with high expertise and longtime experience with the patients with MACI. We will refer to these people as the domain experts.

Before planning the patient's' workshop, the first author conducted a PD workshop with the multidisciplinary project committee. The PD workshop aimed to achieve the mutual learning [23] between the researcher designer (the first author) and the multidisciplinary project committee compounded by domain experts. The aim was to trigger a design thinking mindset and make the committee grasp the participatory design tools and techniques. The designer had expertise on the design methods and the PD approach, but lacked a thorough knowledge of patients' clinical condition, functioning ability as well as internal procedures and dynamics related to the usage of the "goal plan" in the hospital. On the other side, the domain experts knew the patients and their functioning abilities, but they lacked the knowledge of participatory design methods and techniques. Indeed, before the authors were involved in the project, the multidisciplinary project committee had planned to do interviews with the patients to map their needs.

It was difficult for the multidisciplinary project committee at the beginning to understand the aim of the workshop, but slowly they started becoming more involved. All the subsequent meetings we had with the committee or specific members of the committee had a participatory design approach, where everyone was heard, and the common discussion challenged ideas. The domain experts entered a more creative mindset, and the authors in the role of researchers and designers learned more about the patient's group characteristics and the work procedures at the hospital. The participatory meetings were an essential factor in mutual learning.

The multidisciplinary project committee expertise on their patients helped in *"designing"* better workshops. Among the things discussed in the planning phase were:

<u>Timing</u> – Based on the committee expertise the optimal workshop duration would be 1 hour, divided into two parts each of 20-30 minutes with a 5-10 minutes break in between. In this way it would be possible to have the patient concentrated all the time, without fatiguing him/her.

<u>Number of participants</u> - The committee suggested that the maximum number of participants for workshops was 4. In this way, the patients would feel more comfortable and had the right space to share their stories and their opinions.

<u>Ethical issues</u> – We decided together with the committee that no personal patient data would be recorded. However, the sessions would be audio recorded so we could analyse the data later. The data collected through recordings are considered not anonymous (they are unidentifiable data), so they need to be stored carefully in safe a location. The project agreement was to store all the digital data for the project in a personalised folder at the hospital servers, and that is what we did. Moreover, a consent form including an invitation to the workshop and a description of the project was given to patients by the CU staff members prior to the workshop. The consent form was written in a very simple language to make it easier for the patient to follow. However, it was a detailed and consequently long description, to make sure that all the ethical issues were covered. We agreed with the multidisciplinary project committee about the document. We were aware that the description might be excessive for the patient and could make him/her neglect reading it carefully. To make sure that the patient understood the consent form, one of the staff members at CU would spend time with the patient (that had expressed the willingness to participate) before the workshop, going through the document and provide further explanations where needed.

<u>Patients abilities</u> – a thorough review of the literature [6, 9, 13, 14, 18, 29, 30] about the patients' clinical condition as well as observing the patients in the unit, made clear that it is a very special user group. The symptoms were almost invisible at first sight. Moreover, this is a very diverse user group. When we discussed this with the committee they suggested to focus on the patients' abilities and how to strengthen those during the workshops. The staff highlighted the patients' willingness to share their stories and express themselves both through words and as visual imagery. Writing and visualisation was further combined in workshops.

<u>Facilitators</u> – As the number of participants in a session would be maximum four, we decided that only the first author would participate and facilitate the workshops. Discussing the issue of facilitators with members of the committee we considered an extension of the workshop team by someone from the clinical side that knows how to work with the patient group but is not directly involved with the participating patients. The committee suggested a member from the Learning and Mastering Center at the hospital, which was specialised in providing patient with a deeper insight regarding their health. The member might have met the patients during other activities around the hospital but was not part of the CU staff and not directly involved with the patients. We will refer to this as the knowledgeable third-party. The knowledgeable third-party has the right knowledge and expertise to communicate easily with the patient in case help was needed from the first author. We decided that two facilitators (the first author having design skills and the knowledgeable third-party having domain knowledge) would be sufficient in a workshop with four participants. We used the same knowledgeable third-party representative in the three workshops, so we did not need to explain the goal of the project and the methods in each workshop.

B. Workshops

Three patients' workshops with patients suffering from cognitive impairments and hospitalised at CU were organised. In total ten patients participated. In the first two workshops, we invited patients that had been at the hospital for more than a week, so they were familiar with the document to be redesigned. Four patients participated in the first two workshops. In the last workshop only two patients participated, which were back at the hospital for their follow up week, six months after their discharge.

1) Workshop 1

The workshop was organized in two parts. The first part was "storytelling". The title was "Sharing your experience.". The participants were invited to talk about their experience with the "goal plan" document. They were asked to think and talk about:

- When were they first introduced to the "goal plan" document? How useful was the document in making them better list their goals?
- How had they used the "goal plan" until now, e.g. in a meeting or looking at it in their rooms?
- How had their feelings toward the "goal plan" advanced? How useful was the document to keep them focused on their goals?

The second part was: "What I want my "goal plan" to look like." The technique chosen was drawing and discussion. We asked the patient to think if they had the chance to have a personal "goal plan" document:

- How would they like that to be?
- Think about the kind of information they would want to have there.
- Think about how they could design it a way that could make them look at the document daily.
- Think about how the new design would help them in meetings with the staff members, nurses or doctors. How could the "goal plan" enhance the collaboration?

For the first part, a whiteboard with a print out of the old "goal plan" document in the middle and sticky notes in different colours were provided. The patients could use those to write down keywords to facilitate remembering what they had to say when their turn would come. For the second part, we removed the "goal plan" document and gave each of the participants a white sheet of paper, where they could design their ideal "goal plan".

Reflection-in-action: the patients did not use the sticky notes at all in the first part, and once provided the white sheet of paper for designing, they seemed to step back. Realising the hesitation, the designer and the second facilitator abandoned the drawing idea and started bringing up the questions listed above as discussion points to elicit ideas and needs from the patients. None of the patients designed anything. However, they got the white papers back in their rooms to think about.

Reflection-on-action: Opening the workshop by asking the patients to talk about their experience with the goal plan was problematic. It made the patient focus more on their goals and their specific problems rather than the main project aim, the "goal plan" document layout. Thus, we realised that a narrower approach toward the project aim was needed.

The fear of white paper, the blank page syndrome [31, 32], was made visible in the second half of the workshop. The patients were good at articulating their needs, but they were not able to create a visual image of their needs and consequently design ideas. They got the white paper with them, and only one of the patients came back the next day with a design suggestion and talked personally to the first author. Joyce [33] in her dissertation discusses the role of open option in creativity and finds how the openness of the design space can constrain creativity. Thus, we needed to provide some boundaries in the alternatives in order to increase the chances for creativity from the patients.

The participants had different MACI, which meant they had different levels of articulation abilities and understanding. We noticed that the patients were more focused on discussing personal goals than contributing to the layout of the document. The reflection-on-action in this issue was that more preparatory work from the staff was needed to reinstate the goal of the project to the patient to make sure the patient would have a clearer understanding of the aim of the workshop before entering the room.

After the workshop, project committee representatives met with the designer and the second facilitator and conducted the reflections-on-action as presented above.

2) *Workshop 2*

The reflections on action after the first workshop were taken into consideration before the second workshop.

Thus, the nurses talked with the patients again in the morning of the workshop day, to make sure the patient understood the scope of the project. The workshop was divided into three parts. In the first part, the patients got a version of the old goal plan. Next, to each of the fields in the document, we added two icons, thumb up and down. We asked the patients to mark with thumb up those fields that they considered important for their rehabilitation. Then they discussed the choices among each other. To structure the discussion, the knowledgeable third-party facilitator started going from one field to another and asking patients for their choice. Thus, was easier for the participants to follow and contribute to the discussion. In the second part, the patients were asked to try to rewrite the fields that they found important, in a way that they thought would be easier to understand and read. The third part was called "rearrange". In this part, the patients were asked to rearrange the fields as they wanted, add new fields or, change the structure of the document. At this point, the patient could use the template of the old "goal plan" or get a white sheet and design on it. Colored sticky notes and pens were provided.

In the third part, the participants were also provided with some examples of design made by the multidisciplinary project committee in the workshop with the designer. The patient could have a look at those sketches for a short period for inspiration.

Reflection-in-action: The workshop went well. The patients liked the task-oriented approach of the workshop and they got engaged in the discussion with each other and the facilitators. They started building on the ideas of each other. If someone brought up a new idea that would also spark the discussion among other participants. We observed that the patient could focus better on the general task, marking thumb up and thumb down of the fields in the goal plan and relate their marking to personal stories. The sharing of the stories was very important because it gave the facilitators an opportunity to ask more questions to elucidate meaning of what the patient just said.

Reflection-on-action: One of the lessons learned was that the workshop approach narrowed down to exactly the scope of the project and helped the patient to stay focused on the aim of the project and contribute significantly. While these reflections are not new, they appear very important in the case of patients with MACI. Moreover, the facilitators observed that more work in the pre-workshop phase was beneficial to prepare the patients better for the workshop and enable them to contribute better.

The workshop was organised as a future workshop as presented by [34]. The future workshops have been widely used in PD. The aim is to make people critically discuss a current situation and then envision possible improvements for the issues critiqued in a fantasy phase. After a phase of envisioning any solution, it comes the realisation phase. In the realisation phase, feasible solutions based on what the technology allows are discussed further.

In this workshop we had a slightly changed version of the future workshop. In the critique phase our rhetoric was not regarding critique but more on what the patient liked or not. Providing both the thumb up and down options enabled the patient to think that some things needs to be improved but at the same time there are others that are extremely relevant that need to be preserved, so the patient did not enter a negative mindset. The second part of the future workshop is the fantasy phase. It was clear from the first workshop that the patient could not produce much information while moving directly to the fantasy phase. Thus, before jumping in the fantasy phase we introduced a transition phase, by asking the patient to rewrite some of the things that they thought could be better. By doing this, patients could start envisioning a better solution but still connected to the things that they knew, to the goal-plan that they had seen many times. That "teaser of future envisioning" made it easier to get involved in design in the "rearrange" part and be able design something new or on top of the goal plan or on a white paper. The white paper syndrome was defeated. Figure 1 shows some of the design suggestions provided by patients.

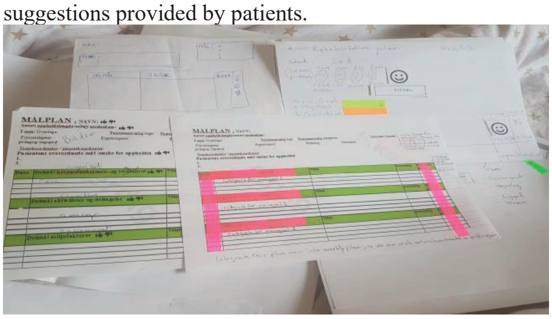

Figure 1. Workshop 2 - Patients' design suggestions

Moreover, the use of exemplars in the "rearrange" part of the workshop, might lead and influence patients' ideas. We were sceptic about the usage of these exemplars, but we wanted to observe what their influence could be and how the patients would react toward that. However, screening the patients' designs did not reveal a noticeable influence from the exemplars presented. Some reflections on this: First the exemplars were presented to the patients in the last part of the workshop, and the patients had already built up a mental vision of their goal plan in the previous phases. Second, the exemplars were exposed only for a short period and were a trigger for possible options of how a goal plan could look like. Integrating exemplars was inspired by research through design and Gaver's work with the ludic design [35-37]. Finally, looking at the amateur designs from the staff inspired the patients to get the colored pens and sticky notes and start designing, overcoming the fear of the white paper. However, this is a very delicate usage and more investigation of the use of exemplars in design sessions should be considered more carefully.

3) Workshop 3

The lessons learned in the second workshop helped in organising the third. As the third workshop had participating patients that were back at the hospital for a follow-up week, their cognitive cognition and understanding of the document was more advanced than the previous patients. We chose to focus more on a long perspective of the rehabilitation process and how the goal plan document could assist in that. The structure of the workshop was the same as workshop two, and the outcomes were comparable.

Refection in-action: The two participants were of different natures. One of them was more expressive, and the other more reserved. Because of this, the facilitator had to make sure that both were getting the same time and attention.

Reflections-on-action on this part where the same as workshop 2.

V. CONCLUSIONS

We will conclude this paper by presenting some meta reflections that we did regarding our experience of doing participatory design with people suffering from mild cognitive impairments. Through these conclusions we aim to open a discussion in PD regarding the work with this specific user group. Moreover, some of the reflections may also be useful in other contexts.

Based on our refection-in-action and reflection-on-action in each of the workshops our suggestions are:

1) *The role of the multidisciplinary project committee compounded by domain experts* - Working with patients with disabilities can be very demanding. Due to that challenge the patient is typically left out of the design process for technologies aimed for them. While PD promotes the participation of patient in participatory design sessions the designers and

practitioner are aware of the challenges that they might face. Thus, help from domain experts that know and have a long experience with the patients is vital for the designer. Moreover, the domain experts in most cases lack design knowledge and tends to fall in the trap of surveys as the only method to understand patient's needs. Hence, both designers and domain experts should contribute in preparations of the PD workshops for patients.

2) *The role of the knowledgeable third-party facilitators in PD workshops* – We observed that the presence of a domain expert that has the ability to communicate with the patients but is not directly involved with them had a positive effect. First the patient has someone from the hospital in the workshop so that they can feel safer. Moreover, that someone is not a doctor or anybody from the team that the patient is working with at the hospital, which made the patient feel freer to express themselves. Further, the first author felt more comfortable and in control of the situation with a hospital representative that would smooth any kind of situation that could be presented.
3) *Short workshop duration and Limited number of participants* – Keeping the workshops in one-hour sessions and with up to four participants had positive results in our case. The patients expressed that they enjoyed the participation without fatiguing him/herself.
4) *Avoid the white paper syndrome* – As described by [33] the white paper was a limit in the creativity of the patient. They were not able to envision a new layout. A more task oriented, and creativity evoking technique was needed.
5) *Positive rhetoric and the teasers of future envisioning* – Applying future workshop technique in a more task oriented and transitional way than the original version of Jungk [34] made the participants more engaged during the workshop and later able to design their version of the goal plan as presented in Fig.1. We applied two changes in the future workshop technique. First, we used a positive rhetoric in the critical phase and did not only focus on critique. For instance, we used words like good and better and focused on improvement.

   The other difference was that we presented what we called a teaser of the future envisioning, were the participants could think about a new version of future changes but keeping that still connected with what they knew and they were familiar with (in connection with the old "goal plan").
6) *Try out the power of exemplars as a way to enhance creativity* – the usage of examples of designs needs more consideration and further study. However, we can state that it was helpful for our participants which had different MACI. It aided their creativity by making them think out of the box. Moreover, we found that the amateur examples presented helped the participants relate more to them and enhanced their ability to break the white paper syndrome and freely draw their ideas.

Finally, in this paper we aimed to present a story of how we applied PD with MACI. We used the reflective practitioner approach to present our reflection both in and on action. Moreover, we concluded with some meta-reflections on our process. These meta-reflections can be taken in consideration, discussed and expanded with more insights in other projects in the future.

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PAPER VI

ACHI20

Çarçani, K., Grisot, M., and Holone, H. (2020). Designing Personal Health Records for Cognitive Rehabilitation, In (ed.), ACHI 2020, The Thirteenth International Conference on Advances in Computer-Human Interactions. International Academy, Research and Industry Association (IARIA). ISBN 978-1-61208-761-0. konferanseartikkel. pp. 250 - 259

Designing Personal Health Records for Cognitive Rehabilitation

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***Abstract*—Personal Health Records (PHRs) are digital tools that give people the possibility to have access and control over their health data. They are usually used in situations when the patient is home or in casual encounters between the patient and the healthcare practitioner. Current related literature does not discuss much in terms of PHR usage in hospitals and possible implications for designing such PHRs. In this paper, we present the case of cognitive rehabilitation in a rehabilitation hospital. Patients in rehabilitation should take a leading role in their treatment as a prerequisite for more beneficial rehabilitation. We have analyzed the cognitive rehabilitation case and present a set of six design implications for designing a PHR for the patients in cognitive rehabilitation during their time at the hospital. We discuss these implications from a Computer Supported Cooperative Work (CSCW) perspective, where the PHR has been conceptualized as hybrid information spaces compounded by personal and Common Information Spaces (CIS). We found, that in cognitive rehabilitation, an important element for designing a PHR is its role not only in creating the possibility of sharing information between the patient and the healthcare practitioners, but, at the same time, offering some mechanisms for coordination between them as an incentive of recognizing patients work in the division of labor and helping the patient take more control over his/her rehabilitation.**

Keywords-PHR; cognitive rehabilitation; coordination mechanisms; patients empowerment; CIS.

I. INTRODUCTION

Personal Health Records (PHRs) are defined as "digital tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" [1]. PHRs emerged from the need of patients to take control of their health information and contribute to it [2]. Commonly, patient health information has been stored in Electronic Medical Records (EMR), which are used by healthcare practitioners to facilitate the management of patient's treatment and also as a cooperative tool with other healthcare practitioners [3]. However, despite an increasing requirement in health policies in recognizing patients' role as being active participants in their care, patients still do not have access to EMRs and their own health information. Often, the only way they get access is by obtaining a paper copy of their records. Thus, patients collect paper documents and create their own big paper folder that they usually bring over in consultations. This practice has limitations in terms of how the information is stored, retrieved, and shared. In response to these limitations, PHRs emerged around two decades ago to give patients the possibility to have access to their health data and also be able to generate more health information that they can share with whoever they want.

PHRs have been discussed in the literature under different lenses, and different types of PHRs have been developed. The CSCW field has contributed to increasing the understanding of the cooperative work in healthcare and introducing a set of digital artifacts that facilitate cooperation [4], offering in this way, better services to the persons in need. From a CSCW perspective, the PHR is a collaborative tool between patients and healthcare practitioners. The PHR has been conceptualized as an information space of a hybrid nature [5]-[7] representing a tool that integrates personal and interpersonal/common information spaces. In this paper, we follow this line of work and are interested in both the design of PHRs and their conceptualization as collaborative tools. Therefore, we address the following research question: "*How to design a PHR for cognitive rehabilitation?" and "How can this contribute to conceptualize PHRs?"*

Specifically, we analyze the collaborative use of a PHR in the hospital context, while patients are still hospitalized. PHRs are mostly designed to support the collaboration between the patient and health practitioners when the patient is home or when s/he has casual encounters with the healthcare practitioners. We argue that, in order to support collaborative work in the hospital context, the PHR needs to be designed differently. In addition, we also argue that PHRs need to accommodate the specific needs of the patient's clinical problem. Hence, in this paper, we identify and discuss implications for the design of a PHR in the case of patients in cognitive rehabilitation in a rehabilitation hospital. In this context, patients have to actively participate in care practices (not only receive care). Cognitive rehabilitation is a special rehabilitation program that is usually offered in rehabilitation hospitals to patients who suffer from some cognitive impairments after Acquired Brain Injury (ABI) caused mainly from stroke or accidents [8]. We have investigated the cognitive rehabilitation process in the Cognitive Unit (CU) of a rehabilitation hospital in Norway and defined a set of implications for the design of a PHR in such a setting. We discuss the PHR design implications in relation to the current conceptualization of PHRs within CSCW research and contribute to a better understanding of such tools.

In Section II, a description of our main concepts is presented. Section III gives an overview of how the data was collected and analyzed. Section IV is a detailed presentation of the practice of cognitive rehabilitation as a summary of our empirical study. Section V presents a set of implications for designing a PHR used in cognitive rehabilitation grounded in our empirical findings. In Section VI, we discuss the implications for design with a more conceptual perspective drawn from the existing conceptual discussion of PHRs in CSCW.

II. CONCEPTUAL GROUNDING

In this section, we present more in-depth the main concepts for this paper. Initially, we present PHRs and how they have been defined and described in the literature. Further, we present how PHRs have been conceptualized in CSCW as a hybrid information space. Moreover, we focus on the CIS as a concept and finally describe the concept of coordination mechanisms as a parameter of CIS and relevant for our discussion later in the paper.

A. Personal Health Records

PHRs have been defined generally as Internet-based, lifelong health records that are controlled by the individual and are meant to promote the individual's engagement in his or her health and healthcare [1]. PHRs should be controlled by the patients who should as well enter at least part of the information. Davidson et al. [1] in a PHRs literature review found that there are different types of PHRs. One type of PHRs are those tethered to EMR. In that configuration, part of the PHR information is provided and maintained by healthcare providers. A patient can access the EMR and mostly read through the information, but it is usually not common to have the possibility to edit or change the data in the EMR, even when that is needed, required, and liable for the patient. This does not mean the patient will access the EMR and change the description of their diagnosis. However, the patient can contribute by describing more details about his/her situation, which will then help the doctor make a better diagnosis. Other type of PHRs are those fully controlled by patients, who enter and maintain their own health data [1]. This health data can be brought over to be discussed with the healthcare practitioners during consultations, and the collaboration and interaction happen outside of the PHR. Another type are PHR platforms/ecosystems. They are supposed to be a mix between standalone PHRs and tethered to EMR PHRs, but with a distinction to be untethered from a specific healthcare provider. PHR platforms are supposed to give the patient the freedom to use the PHR independent of where s/he is receiving the treatment. An example of PHR platforms from the Norwegian healthcare has been described by Vassilakopoulou et al. [7]. Helsenorge.no is a patient platform where the patient can find part of his/her health data arriving from different health settings. The aim of helsenorge.no is to give patients a space/platform where they can find health data such as diagnosis (epicrise), have the possibility to communicate electronically with their General Practitioner (GP), check their vaccine history, their medicine, etc. and possibly more services in the future.

PHRs are considered to have the potential to contribute to patients' empowerment by implying changes in the way healthcare is delivered and give patients the possibility of being more involved and getting more control over their care [2]. However, their usage is still low, and there is limited research on how PHRs can empower the patients in having more control and being involved in their care.

Creating PHRs is associated with multifaced socio-technical problems attributed to their role of connecting multiple parties and social actors [9]. From a patient perspective, a PHR is valuable for accessing information and sharing health information with the ones s/he wants. From a healthcare practitioner perspective, the usage of a PHR could contribute to better coordination with the patient and the possibility to access information that surpasses organizational boundaries.

B. PHR as Hybrid Informations Spaces

Researchers in CSCW have been discussing how to conceptualize PHRs. Cabitza et el. [6] argue that conceptualizing PHRs as tools that can just support the flow of information mitigates their full potential to be more collaboration and communication oriented. Thus, they suggest framing PHRs as hubs where patients and healthcare practitioners meet to enhance a collaborative relationship. Cabitza et al. [6] have defined the concept of InterPersonal Health Record (IPHR) as a hybrid electronic record that merges the typical EMR and PHR related features that aim at enhancing “relationships, communication, and collaboration between citizens/patients and their healthcare practitioners” [6]. The emphasis on the interpersonal aims to highlight the involvement in the management of care of both patients and healthcare providers. Cabitza and Gesso [5] describe MEDICONA as an example of an IPHR. MEDICONA implements the concept of a shared record among different user types, in addition to electronic messaging [5] and is described as an IPHR. Further, they discuss how the IPHR can be conceptualized as a CIS, where patients and healthcare practitioners can access the information that they need regarding health management in a common space. This conceptualization is compatible with Lahtiranta et al. [10] health spaces defined as collaborative information space for patients and health providers, which are not limited only to healthcare-related encounters.

Unruh and Pratt [11] identify a set of functional requirements for an information space designed explicitly for patients’ cooperation with clinicians. They define explicit representations and increased interaction as a way that CIS can facilitate cooperation between patients and their clinicians.

Recently, Vassilakopoulou et al. [7] have conceptualized PHRs as information spaces of a hybrid character. They state that “PHR can be more than a private tool, serving as CIS that straddles work and non-work contexts, bringing together participants – patients and professionals – in a collaborative relation”. Thus, considering PHR as personal information space (serving sensitive health information management need) and CIS (stressing the cooperative dimension of the patient- healthcare practitioners’ relations). They have analyzed and discussed two cases of a PHR: a) MyHealth, which gives the possibility to the patient to access and store personal health information, and supports electronic exchanges between patients and healthcare providers. Moreover, it offers connections to several existing systems and the possibility for other applications to connect and extend the core functionality [7], and b) MyBook, which facilitates information sharing between the patient and his/her GP [7]. The cases described, such as MEDICONA, MyHealth, and MyBook, are examples of PHRs which facilitate communication, awareness through records, and collaboration based on the information shared in the common space. However, this literature considers mainly cases when the patient is outside of the hospital and has only occasional health encounters with the healthcare practitioner. The literature on PHRs has not yet addressed the use of PHRs in hospital/clinical context. In this context, it is assumed that patients do not need to have access to their health data as they are in close contact with clinicians. However, as patients are asked to cooperate/work together with clinicians (and not just receive care), they also need tools that enable them to take up this role. Thus, the case described in this paper contributes to the conceptualization of PHRs in a hospital setting in a context where the patient has to actively participate in the care practices (not only receive care).

C. Common Information Spaces

In CSCW, PHRs have been defined as CIS or hybrid information spaces. While personal information spaces refer to patients' individual needs in managing health information that is personal to them, the concept of CI has been discussed in CSCW. In this subsection, we will present a deeper understanding of CIS as a concept.

CIS is a conceptual framework in CSCW which highlights the relationship between actors, artifacts, information, and cooperative work [12]. The aim is to provide an analytical tool that can inform developing systems that can support cooperative work [12].

CIS "encompasses artifacts that are accessible to a cooperative ensemble as well as the meaning attributed to these artifacts by the actors" [12]. In cooperative work settings, actors are interdependent. This requires that they coordinate who is doing what, when, and why [13]. Thus, what is called articulation work takes an important role. Articulation work as the supra type of work, which is necessary for the division of labor [12][14], can be facilitated by the usage of artifacts or mechanisms of interaction [15]. According to Schmidt and Bannon [12], CIS is necessary for distributed cooperative work to maintain some form of shared and locally and temporally created understanding about objects in the CIS.

An important characteristic of CIS is the openness and closure and the need for a balance between the malleability of information and the need for some closure to allow for translation among communities. In making this possible, a balance of interpretations among different webs of significance (as called by Bossen, representing people from different groups) is needed [13]. Hence, CIS requires a new type of articulation work, which makes possible the coordination of interpretations.

In healthcare, there are some examples of CIS, such as [16] in which the influence of the physical position of artifacts used in a CIS in a hospital is investigated. In [17], CIS were investigated in emergency teams in hospitals.

Bossen [13] describes seven parameters of CIS such as the degree of distribution; the multiplicity of webs of significance; the multiplicity and intensity of means of communication; the level of required articulation work; the web of artifacts; the immaterial mechanisms of interaction and the need for precision and promptness of interpretation. Bossen [13] as well build his analysis of CIS in a hospital ward.

A relevant parameter for this paper is the "web of artifacts" described as material mechanisms of coordination to make possible cooperation among the distributed actors and having a better overview of the state of the work possible. Based on this definition, a PHR as a material artifact in the hand of the patient in which the patient can communicate, collaborate, cooperate with the healthcare practitioners, is a mechanism which materializes a CIS between the patient and healthcare practitioners.

In the literature, different types of artifacts that support a CIS are described. Bossen refers to the web of artifacts as material coordination mechanisms by referencing to coordination mechanisms as defined by Schmidt and Simonee [15]. However, Bannon and Bødker [18] have discussed that what is defined as boundary objects from Star and Strauss [19] can be as well used as a means for sharing items in the CIS. Thus, another type of web of artifact in CIS. The concept of boundary objects and coordination mechanisms have differences, as discussed in [20]. In this paper, we are particularly interested in coordination mechanisms and will get back to this concept in our discussion.

D. Coordination Mechanisms

Coordination mechanisms have been defined [15] as "a specific organizational construct, consisting of a coordinative protocol imprinted upon a distinct artifact, which, in the context of a certain cooperative work arrangement, stipulates and mediates the articulation of cooperative work to reduce the complexity of articulation work of that arrangement." Thus, coordination mechanisms are artifacts which aim to reduce the complexity of the division of labor in a cooperative work setting and make cooperation possible. The concept of the coordination mechanism, as defined, describes a material artifact. This approach has been considered narrow by Bossen [13], who emphasizes that organizational structures and division of labor also facilitate coordination of work since they explicate who does what and when. Hence, as another parameter of CIS, Bossen lists the immaterial mechanisms of interaction for these other constructs, which facilitate articulation of cooperative work. Coordination mechanisms aim to coordinate activities among semi-autonomous actors who should have a certain level of consensus in order to get the job done [20].

The PHRs that have been described in the literature as CIS [5][21]-[22] or hybrid information spaces [7] show mostly cases of artifacts that offer a space where the information is shared, and communication and collaboration are supported, thus resembling coordination mechanisms. However, they lack an aspect of a more cooperative relationship between the patient and the healthcare practitioners, where the patient has an active role in his/her care by taking over tasks and work in the division of labor. Moreover, cases of CIS discussed in healthcare [13][16]-[17] are mostly focusing on hospital wards and describing the need for sharing information among healthcare practitioners. The patient's voice and visibility in the process lacks. Hence, in this paper, we describe, in the next section, a case of a hospital ward where the CIS also involves the patient. Moreover, the requirements for a PHR are not only communication and sharing information but entering a cooperative relationship where the patient and the healthcare practitioners supporting him/her are interdependent on each other.

III. DESCRIPTION OF THE COGNITIVE REHABILITATION EXISTING PRACTICES

We studied the process of cognitive rehabilitation in the CU of a rehabilitation hospital in Norway. The unit is specialized exclusively for offering cognitive rehabilitation. Cognitive rehabilitation is a special rehabilitation program that is offered to people that suffer from cognitive impairments after an Acquired Brain Injury (ABI). ABI is brain damage acquired after birth. The causes of ABI can be "from a traumatic brain injury (i.e., accidents, falls, assaults, etc.) and non-traumatic brain injury (i.e., stroke, brain tumors, infection, poisoning, hypoxia, ischemia, metabolic disorders or substance abuse)". The cognitive rehabilitation aims to support the patients in therapeutic manners, thus, either improving his/her functions in daily life or helping the patients to find alternative ways for compensating the lost functions through additional aids. Rehabilitation, as defined by the Norwegian Health Authorities [23], requires a multidisciplinary team that works together with the patient during rehabilitation. The multidisciplinary team involves different healthcare practitioners.

In our study in cognitive rehabilitation, the multidisciplinary team is usually compounded by the medical doctor, a nurse, an occupational therapist, a physiotherapist, a psychologist, a social worker, and a speech therapist. This team assists the patient throughout the 5 five weeks of rehabilitation at the hospital. Each offers specialized care to the patient based on their domain of knowledge.

Rehabilitation is based on the goal-setting theory. This theory is defined broadly as a process in which the patient and members of the multidisciplinary team agree on a set of rehabilitative goals to be achieved during the rehabilitation program [24]. Goal-setting is not only an administrative tool, but it is considered a clinical intervention. [24]. It has been shown that setting personal goals increases the possibilities of behavior change by increasing motivation (the desire to act in a particular way) [25].

In the CU, the rehabilitation process is built based on the goal-setting theory. Thus, a patient, in collaboration with the multidisciplinary team, has to decide on a set of goals that s/he wants to work with during rehabilitation. Goals are mostly long term. As the time stay at the hospital is only for five weeks, the patient and the multidisciplinary team during the first week should agree on the things to prioritize for those five weeks and decide on a set of sub-goals for each main goal. The sub-goals should be SMART (Specific, Measurable, Achievable, Realistic, and Timely). As rehabilitation targets the increase in the patient's functional level in his/her daily life, the involvement of the patient in defining the rehabilitation goals is essential. The first week at the hospital, the patient meets with all the members of the multidisciplinary team one by one. In the ideal scenario, the patient comes already with a set of predefined goals, written by himself/herself. However, in many cases, the patient is not able to define his/her rehabilitation goals, and the multidisciplinary team members should help him/her. If the patient is not cooperating with the team, it is a risk that not relevant and specific goals would be set, and the result of the rehabilitation will be mitigated. The refining of goals comes together with the definition of a set of interventions that the patient would go through at the hospital to be able to achieve the goals. Interventions are defined as "an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions" [26]. It is absolutely relevant to the involvement of the patient in the process, so the patient later understands why s/he is doing different activities at the hospital.

The goals, respective sub-goals, and the interventions for each sub-goal are stipulated in a document called the goal plan document. This document is originated in the hospital EMR as part of the patient record. The goal plan is conceptualized to be shared with the patient as the main document of coordination between the team and the patient in rehabilitation. The document is designed to show the goals, sub-goals, and interventions, the team member that is responsible together with the patient for a specific intervention, and some more mechanisms that can help keep track of how the patient is advancing during rehabilitation. As the document is in the hospital EMR, the patient cannot access it. So, a printed version is given to the patient from the start. The electronic document is then shown during a meeting where all the multidisciplinary team, the patient, and if willing any of the patient's kin would go through the goals and agree on the final version. The final version will then be printed out and given to the patient.

During the time at the hospital, the patient receives a weekly plan every beginning of the week. The weekly plan involves all the activities that the patient should do during the week. The weekly plan is not part of the patient records in the EMR. It is maintained in a shared word document and printed out for each of the patients. If changes are made, the team member that implements the change can print another version or, in some cases, the patients write over the paper. The activities in the weekly plans should relate to any of the interventions in the goal plan and consequently contribute to the patient's sub-goals. This connection is very important to be highlighted for the patient as part of his/her rehabilitation process. However, the restriction that the current procedure and materiality of the artifacts imposes is not exploring the whole potential.

When the five weeks of rehabilitation are finished, the patient returns home. S/he can continue rehabilitation by his/her own or receives additional help from local rehabilitation therapists. The plan on how the patient should continue rehabilitation home has been made since s/he was at the hospital. The therapists at the hospital have established some connections with local therapists. It is important that the patient continues training with rehabilitation goals and sub-goals and keeps us with respective interventions as taught at the hospital.

IV. METHODS

A. Data collection

The data that we have analyzed for this paper has been collected in two phases under the umbrella of the same project called “Patient Empowerment in Cognitive rehabilitation through the use of technology”, which is a joint research initiative between a rehabilitation hospital and a university college in Norway.

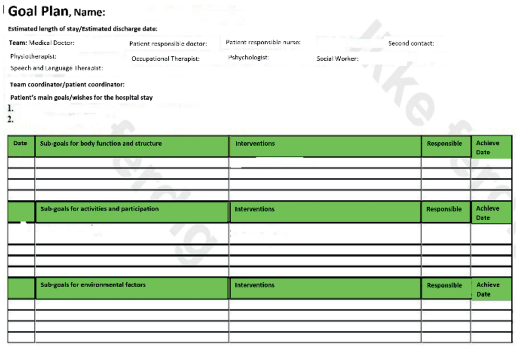
Initially, as part of the initiative in boosting patients' involvement in their rehabilitation, the hospital decided to redesign the goal plan document and the procedures surrounding it. To redesign the document, a Participatory Design (PD) approach with workshops was taken in April-May 2018. First, the first author of this paper facilitated three workshops with a total of 10 patients, asking how to redesign the goal plan document (Figure 2) to make them want to engage more in their rehabilitation (more in detail this has been reported in another publication [27]). Second, the first author of this paper organized two PD workshops with the multidisciplinary team at the CU (20 participants). The healthcare practitioners were presented with a list of requirements from the patients' workshops and were invited to discuss these requirements and propose a new design of the document which would fulfill patients’ requirements and, at the same time, fit within their routines and procedures. With the data collected, a redesigned document (as shown in Figure 2) was launched in June 2018 and has been in use ever since. Data collected where audio recordings of the workshops and designs of the new goal plan version from each of the participants. All participants signed a consent form before the workshops, and the data collected has been stored in safe locations at the hospital premises.

In the second phase, ethnographic observations of the rehabilitation process at the CU from an extended period of 6 months, August-December 2018, were conducted. Together with the CU management, we decided that for the ethnographic observations, the researcher (first author here) should shadow each of the health practitioners in the multidisciplinary team for a short period of time. This would minimize the stress of the patients and would give us the possibility to investigate the illness journey of more patients. The first author shadowed two occupational therapists respectively for 4 and 3 working days (8 hours shift during the day shift because in the afternoon most of the patients would go in their homes and no rehabilitation activities were planned at the unit) and participated in activities with 12 patients, one nurse for 6 days and met 5 patients, one physiotherapist for 4 days and met 8 patients, one speech therapist, one social worker for 4 days and met 8 patients and one psychologist for 1 day and met 1 patient. Handwritten notes where taken while observing. These notes where expanded with details at the end of each day when transcribed digitally. Digital notes were saved in a folder in the safe hospital network that the first author can access through an encrypted laptop given by the hospital. The staff member asked the patients for consent before the researcher would participate in any patient-staff meeting. This was documented by signing a consent form.

B. Analysis

Overall, a qualitative interpretative research approach [28] was adopted. First, the data collected were analyzed with the aim of defining a list of implications for designing a PHR for patients in cognitive rehabilitation. Second, reflections on these implications with the theoretical lenses of hybrid information spaces [7] were conducted. The principles defined by Klein and Myers [28] were used to do an interpretive analysis of the data collected in the two phases described in the previous section. We describe the process more in detail below.

Initially, the first author analyzed the audio-recorded data from the workshops and the designs of the patients and staff. Considering that the design requirements that emerged during the workshops were focused on the redesign of the goal plan document, which is a patient health record, the first author interpreted them with the perspective of possible design implications for a PHR. Moreover, the implications for design that emerged during the first iteration of interpretative analysis were supplemented and refined while analyzing notes from the observation period. The first author used a grounded theory approach to analyze the observation notes and defined a set implications for designing a PHR in cognitive rehabilitation in a hospital.



Goal Plan, Name:

Estimated length of stay/Estimated discharge date:

Team: Medical Doctor: Patient responsible doctor: Patient responsible nurse: Second contact:
Physiotherapist: Occupational Therapist: Pshychologist: Social Worker:
Speech and Language Therapist:

Team coordinator/patient coordinator:

Patient's main goals/wishes for the hospital stay
1.
2.

Date	Sub-goals for body function and structure	Interventions	Responsible	Achieve Date
	Sub-goals for activities and participation	Interventions	Responsible	Achieve Date
	Sub-goals for environmental factors	Interventions	Responsible	Achieve Date

Figure 1. A translated version of the goal plan document before the redesign.

The list of implications was then discussed and refined with the other two authors who took a critical stance toward the findings. In the discussion, we (the three authors) reflected on implications for design, which were considered desirable for both the patients and staff.

V. IMPLICATIONS FOR DESIGN FOR A PHR IN COGNITIVE REHABILITATION

The case of cognitive rehabilitation in a rehabilitation hospital and, to a certain extent, rehabilitation in general either in the hospital or in the local communities has its own specificities. Below we present a list of implications for designing a PHR for cognitive rehabilitation.

1) *Enhance the existing shared artifacts* – The goal plan document and the weekly plans are an example of artifacts that are already implemented at the hospital and support cooperation and coordination between the patient and the multidisciplinary team, as presented in Section III. These artifacts are special to the rehabilitation process and the organization of care based on the goal-setting theory. From our data, we found that patients and the multidisciplinary team consider the goal plan an important element of the rehabilitation. Thus, designing a PHR for cognitive rehabilitation at the hospital should take into consideration these good practices in place and enhance the experience.

The goal plan document is compatible with the definition of PHRs, as stated in Davidson et al. [1]. With goal-setting as not only an administrative tool but as a clinical intervention [24], the document represents a health record that is supposed to be controlled by the individual and is meant to promote the individual's engagement in his/her health and healthcare [1]. The goal plan document is a limited version of a PHR as the patient cannot directly generate information (write goals or add appointments suggestions in the weekly plan), and every change in the health record is mediated by health professionals. Control allocation has been defined as a design tension when designing PHRs by Vassilakopoulou et al. [7]. However, the goal plan is still a special and good practice in clinical rehabilitation where the patient is supposed to not only receive care but co-construct care together with the multidisciplinary team. The team and the patient consider problematic that the goal plan is in the EMR of the hospital. The paper version that is given to the patient limits the options for using the goal plan. In the workshop and during observation, all the team members and the patients pointed to the need for digitalizing the goal plan and giving control to the patient. One other important insight is that the team would like a PHR for the patient, but they as well require this PHR to be tethered to the EMR [1] to avoid double work in reporting.

2) *Implement elements of coordination* – During the workshops, we found from both the patients and the team that when defining goals, the best scenario would be to see the patients themselves writing their rehabilitation goals. In this scenario, the multidisciplinary team would check the goals the patient has defined, then discuss them with the patient in a meeting. During the meeting, the staff participating would then change the goals based on what is discussed with the patient. The patient could then access the document and make additional changes. Finally, both team and patient, if agreed, would sign the final version of the goals during the so-called 'goal meeting'.

However, during observations, we found that the patient involvement in defining his/her goals is mitigated because s/he doesn't have direct access to the goal plan. The team compensates for the lack of patient involvement, but this can influence the result of the rehabilitation.

An Occupational Therapist during an in-situ interview stated that "an important aim of the treatment is to increase patients' knowledge on how to set rehabilitation goals and get to know which activities they can do to achieve the goals". Thus, rehabilitation is not only a matter of giving a service to the patients, but it is about increasing patients' health-literacy as a way to achieve self-management of their own condition. As a way to give patients more control over their rehabilitation and increase health literacy, we found that patients and the team members consider relevant assigning patients a role in the division of labor of the treatment and make this explicitly stated.

Take the goal plan with you in every session

Goal Plan

Name:.................................
Main Responsible for the goals

Estimated date of discharge:

My goals for the stay at the h

Goal 1:

Goal 2:

Goal 1:

0-10 my sub-goals score/☑ my activities

Starting Point | Week nr | Week nr | Week nr | Week nr | Follow up week

Sub-goal 1: 0-1-2-3-4-5-6-7-8-9-10

Interventions

Responsible

Sub-goal 2:

Sub-goal 3:

Notes: In order for you and your
with one in your team. The ques

Figure 2. The redesigned goal plan document.

PHRs give people the possibility to look into and generate some of their health data and as well communicate and collaborate with a healthcare practitioner [1]. From the analysis of our data, we find that a PHR in cognitive rehabilitation should support not only common information and communication but also a cooperative work relationship between the patient and the multidisciplinary team. Hence, the PHR should facilitate the tasks that the patient should do and coordinate these patient's tasks with the tasks of the healthcare practitioners.

3) *Support different representations* – As stated above, rehabilitation goals can be divided into sub-goals, and for each sub-goal, there is a set of interventions. This tree structure is seen differently by the patient and the multidisciplinary team perspective. For the patients, the rehabilitation goals relate to the need for functioning in everyday life and should be articulated in that way. For the multidisciplinary team, the decision on rehabilitation goals and interventions is influenced by rehabilitation theories [29]-[31]. Thus, different representations of the same information are needed. During the PD workshops, we found that a classification of goals as defined by the International Classification of Functioning, Disability, and Health (ICF) [32] (as in Figure 1) was preferred more from the team. However, patients in workshops expressed that they did not relate to the classification of goals based on ICF and that "did not make sense" to them. One patient said, "is easier.. I want to have my goals, sub-goal and interventions… is that simple". Hence, designing a PHR for cognitive rehabilitation while the patient is at the hospital requires that the health information shared with the patient should be explicitly represented in a way that the patient can understand.

The case of a representation of a health record in a format that relates more to healthcare practitioners is very common. PHRs should surpass this downside of the current way of delivering healthcare and support an explicit representation of the information for the patients – in a way that facilitates how they interpret the information. The label of this implication for design is adapted from Unruh and Pratt [11]. Such an implication for design is not unique to cognitive rehabilitation, but it is of extreme relevance in the case of cognitive rehabilitation due to the cognitive impairments that the patients in this patient group face.

4) *Integrate elements that can support enhanced interactions* – "We want to be asked how we feel in relation to our rehabilitation goals every week," said one of the patients in the workshops. While at the hospital encounters between the patient and healthcare practitioners is quite intense, our participants in the workshops expressed that they would like to have more encounters with the multidisciplinary team where they can share their opinion on how rehabilitation is progressing. It is relevant to consider this when designing a PHR that supports cognitive rehabilitation. The PHR should integrate elements that can support the patient to have their say in rehabilitation and share their feedback with the multidisciplinary team.

However, in interactions, the two sides that should interact should agree. We found that the team agrees that more interactions with the patient to ask about their perception of achieving goals would benefit the patient. This, however, would require changes in their routines, and they cannot be overwhelmed with data and consultation sessions (in analogy with Tang and Lansky [33]). For example instead of asking the patient every week on how they feel the PHR can support the patient to enter this information every week in his/her health data and be able to have maybe a meeting of discussing the information saved in the PHR every second week with one from the multidisciplinary team members. The interaction with the team will increase as the patient is giving feedback. Moreover, the encounter between the patient and the team member would be more meaningful as the discussion can be facilitated by the information kept track in the PHR on which both sides have agreed and share a common interpretation.

Thus, in cognitive rehabilitation, a PHR that can support and enhance interactions is needed. Moreover, the PHR should be flexible enough to support the negotiation of these interactions. This implication for design is more specific to the case of using PHRs in hospitals where the patient has more possibilities of encounters with the healthcare practitioners.

5) *Facilitating for personal spaces and having the possibility to negotiate boundaries for cooperation and coordination* – We found that patients' rehabilitation is individual. A PHR that aims to support the patient in cognitive rehabilitation should take into consideration the possibility of adapting to specific health information needs for the patient. During the workshops, patients expressed that they would like to have the possibility to keep notes and possibly share some of these notes later with the nurse or someone from the multidisciplinary team. During the observations, we saw patients writing and personalizing the goal plan and weekly plans, as well as other health information given at the hospital. The PHR should offer the patient this additional functionality to enable personalization that can fit the need for personal information spaces.

However, a patient's private space is challenged by the need for cooperation and coordination with the multidisciplinary team. For example, before setting the goals, patients are asked about their life. They receive a file that aims to find out more about their life before and after injury in the attempt to define better rehabilitation goals. Patient information, in this case, can be private, and the patient decides how much to put on the common space. However, not sharing part of this information would undermine the collaboration with the team and the definition of better rehabilitation goals. Thus, a PHR for cognitive rehabilitation in hospital should create the possibility for the patient to a) have personal spaces b) have the possibility to negotiate the boundaries of public and private spaces of information shared and decide where the boundaries stand and c) integrate elements that would motivate patients in expanding boundaries when the discloser of the information can improve rehabilitation.

6) *Support continuity after the hospitalization period* – This requirement surpasses the boundaries of the hospital, but it is necessary to bring up because continuing the rehabilitation therapies started at the hospital is determinative for rehabilitation success.

The rehabilitation is more related to what Wagner et al. [34] describe as the patient's Self-Management and Behavioral Change Support, which needs support for continuity. The patient should have the possibility to continue using a goal plan when moving from the hospital to home. Also, the patient should have the possibility to carry his/her own medical history from the time at the hospital and share that further with others that s/he considers relevant such as kin or local rehabilitation specialists. This is relevant since, in rehabilitation, the patient is not 'cured' once s/he leaves the hospital. Continuity of care is very important in the rehabilitation journey. The rehabilitation is considered finished when the patient achieves a desirable level of function [23].

Finally, the PHR design implications listed here are recommended for the case of cognitive rehabilitation in a rehabilitation hospital. The first two implications for design are special for cognitive rehabilitation. Instead, design implications 3-6 are not exclusive for a PHR in cognitive rehabilitation, but they have become specifically relevant for a PHR in cognitive rehabilitation.

VI. DISCUSSION: A CONCEPTUAL UNDERSTANDING OF A PHR IN COGNITIVE REHABILITATION

PHRs are considered tools that facilitate patients' involvement and give them more control over their health information [2]. Moreover, a PHR shows the invisible work that the patient does in managing his/her personal health records [7]. Our case shows that this is especially important in rehabilitation, where the patient should have higher control over his/her health information, be actively involved, and become the one leading his/her own rehabilitation. This is not only a need but a necessity for the success of rehabilitation [29]. Thus, PHRs are tools that can make a difference in the outcome of the care for patients that have passed the acute phase and are in need of rehabilitation. This paper contributes to the design and construction of a PHR in cognitive rehabilitation specifically, but we also present insights that can be relevant in rehabilitation in general. While in the previous section, we described a set of implications for design that should be taken into consideration in designing a PHR for cognitive rehabilitation based on the analysis of our empirical case, in this section, we will take a more conceptual perspective and discuss the conceptual implications of our study.

A. Hybrid Information Spaces

Vassilakopoulou et al. [7], in their paper, have argued for a conceptualization of PHRs as hybrid information spaces serving personal health information management needs (private information spaces) and facilitating information sharing between patients and healthcare professionals (CIS). We argue that a PHR designed for patients in cognitive rehabilitation also works as a hybrid information space as it is partly personal and partly common. We discuss these two aspects in the following subsections.

1) PHR in cognitive rehabilitation as a CIS - Cognitive rehabilitation involves several actors from different disciplines working together with the patient in an interdependent cooperative relationship and using a series of artifacts to facilitate their collaboration and interpretations. While the multidisciplinary team members have a high level of awareness of the other webs of significance in the team (so a nurse is aware of what an occupational therapist does), the situation differs for the patients. Due to the patients' challenges in cognition, there is a higher need for interpretative articulation work despite physical closeness [18]. Thus, in this setting the CIS includes a) the information that is stipulated in the goal plan b) the information that the patient receives from each of the multidisciplinary team members as part of the rehabilitation therapies and c) the information the patient generates during rehabilitation such as notes or patient journey stories which are then shared with the team. The patient and the multidisciplinary team member have to interpret this information shared in the common space in order to do their part of the work.

Two coordination artifacts [13] are used to facilitate the sharing of the information in the common space between the patient and the multidisciplinary team: the goal plan document and the weekly plan. However, patients and the team have different needs for their interpretative work. The team has a higher understanding of the information. However, they as well are new in the CIS, which is created in the case of a new patient. Thus, they need to put more effort into interpreting the patient's individual and personal needs and goals. In rehabilitation, there are artifacts in place for sharing common information. Thus, enhancing the practice of these existing artifacts by moving from paper to digital should be considered when designing the PHR. Our findings show that a PHR needs to be a flexible tool in order to facilitate the interpretation of the common information. For instance, changes in CIS openness and closeness is important to adapt to each of the patients' requirements regarding the continuity of their rehabilitation and integration with information from other rehabilitation settings (outside of the hospital).

2) PHR in cognitive rehabilitation as a Personal Information Space - The rehabilitation process is individual and closely related to the specifics of the patients. A patient receives personalized information regarding his/her rehabilitation. One of the most important requirements is that patients are able to construct personal interpretations of this information that they can use on their own to continue rehabilitation. Providing the patients with a tool that facilitates the personal health information management based on their individual needs is of a strong relevance in rehabilitation where the increased awareness of patients toward their rehabilitation treatment is the core part of the treatment itself.

Thus, our findings show that in addition to supporting and enabling a common space for information sharing, the PHR should also be designed for personalization.

B. PHR in cognitive rehabilitation as a coordination mechanism

Coordination of activities, as described above, is relevant in rehabilitation. Having a CIS would give access to the same information, but it will not make sure that this will be used in a cooperative way between the patient and the multidisciplinary team. For example, when defining the rehabilitation goals, a PHR conceptualized as a CIS will give the possibility to have the goals shared. However, it will not guarantee that these goals would be written or initiated by the patient. To create a cooperative procedure that would support the process of rehabilitation and give patients a more explicit role in their rehabilitation, the PHR should integrate a requirement that the patients write the first version of the rehabilitation goals, and then the team looks at it and maybe approves the goals. Bossen [13] has described a set of parameters of CIS. Among the parameters are the web of artifacts, described as mechanisms that support the cooperation and facilitate interpretations in the CIS [18]. Bossen [13] further refers to this as coordination mechanisms described by Schmidt and Simonee [15]. Coordination mechanisms are not only means for sharing items in a CIS. They have the characteristics of supporting the coordination of activities in a cooperative setting where cooperative work between interdependent actors is happening. We have described coordination mechanisms in Section 2.D. In analogy to the characteristics of coordination mechanisms, the actors that are seeking cooperation - the patient and the multidisciplinary team - are interdependent in rehabilitation. They are as well interdependent in defining the goal plan and keeping track of activities during rehabilitation. Moreover, consensus is required between the patient and the team in order to do the interventions in rehabilitation. Thus, in cognitive rehabilitation, coordinating activities is needed in addition to accessing the CIS.

So, designing a PHR in cognitive rehabilitation accounts for a coordination mechanism between the patient and his/her multidisciplinary team. This will contribute to making explicit the patient contribution in his/her rehabilitation, increase the level of awareness regarding the activities that happen as part of his/her treatment, and as well influence patient’s health literacy, involvement, participation in decision-making, and self-management.

Hence, we conclude that a PHR in cognitive rehabilitation can be conceptualized as a hybrid information space [7]. However, within the hybrid information space, our findings also show that the PHR should also work as a coordination mechanism [15] that recognizes the patient's position as part of the division of labor, supports the process of rehabilitation, and empowers the patient. The PHR as a coordination mechanism would vary based on the diagnosis, patient's ability, the scale of willingness to be involved in his/her treatment, and the medical practitioners' commitment to supporting the patient. How much coordination and on what tasks the patient can take charge should be considered in individual cases. However, starting by discussing and recognizing the PHR as a coordination mechanism contributes to making the patient role in his/her care more active than just the receiver of care. A feeling of involvement, even in small tasks, will increase the perceived empowerment. The conceptualization of the PHR as a coordination mechanism also puts the burden on the staff as an important element in the coordination. Thus, the patient can feel safer and not left alone.

VII. CONCLUSION AND FUTURE WORK

In this paper, we presented the case of cognitive rehabilitation. We defined a set of implications for design of a PHR for a patient in cognitive rehabilitation such as: Enhance the existing shared artifacts; Implement elements of coordination; Support different representations; Integrate elements that can support enhanced interactions; Facilitating for personal spaces and having the possibility to negotiate boundaries for cooperation and coordination; Support continuity after the hospitalization period.

Moreover, we discussed the design of a PHR for cognitive rehabilitation in hospitals under the current conceptualization of PHRs within CSCW as hybrid information spaces compounded by personal information space and CIS. We conclude that a PHR in cognitive rehabilitation can be conceptualized as a hybrid information space [7]. However, its development as a coordination mechanism that recognizes the patient's position as part of the division of labor will support the process of rehabilitation and empower the patient. The analysis of our case also contributes to the design of PHRs in the context of the hospital. Cognitive rehabilitation represents a very special case of hospitalization. Thus, as part of our future work, we want to investigate further if the implications for design for this specific case of hospitalization can be replicated in other cases or not. Moreover, the implications for design presented in this paper will be the bases for developing a PHR for cognitive rehabilitation as part of an inter-regional funded project by 2021.

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PAPER VII

IRIS SELECTED 18

Çarçani, K. and Holone, H., "Boundary Objects or Coordination Mechanisms?" (2019). Selected Papers of the IRIS, Issue Nr 9 (2018). 4. Available at: https://aisel.aisnet.org/iris2018/4

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Selected Papers of the IRIS, Issue Nr 9 (2018) Scandinavian (IRIS)

Spring 6-2-2019

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Recommended Citation
Çarçani, Klaudia and Holone, Harald, "Boundary Objects or Coordination Mechanisms?" (2019). *Selected Papers of the IRIS, Issue Nr 9 (2018)*. 4.
https://aisel.aisnet.org/iris2018/4

Boundary Objects or Coordination Mechanisms?

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Abstract. Boundary Objects (BOs) and Coordination Mechanisms (CMs) are terms with a long history in CSCW. They have both been used widely since their initial definition. We find the concepts used in the same settings to describe some form of cooperation among different peoples or group of people. Sometimes it seems that the choice of concepts has not been thought through. Thus, in this paper, we give a detailed description of both concepts, and then we discuss them side by side by highlighting six issues that researchers should take in consideration before defining an object as a coordination mechanism or a boundary object.

Keywords: Boundary Objects, Coordination Mechanisms, CSCW

1 Introduction

Computer Supported Cooperative Work (CSCW) is the scientific field concerned with how cooperative work can be supported by means of computer systems [1, 2].

During more than three decades of the establishment of the field [2], many concepts and theories have been articulated in CSCW. Boundary Objects (BO) and Coordination Mechanisms (CM) are terms with a long history in CSCW. In this paper, we aim to discuss both concepts and clarify what constitutes one or the other. Moreover, we aim to define some important issues to consider when evaluating if an object used among different actors or groups of actors is a coordination mechanism or a boundary object.

Our interest in this discussion originated during a conversation about the application of these concepts in a research project where we were investigating how technology could support a patient journey. The journey starts at the hospital and moves into the local community and local care services, and sometimes back to the hospital. Initially, we were discussing the concept of BOs as the right notion for a system that would support the communication and cooperation among the hospital and the local care as two different social worlds. Further, we started considering the concept of CM as an object that facilitates cooperative work. We noticed that the CM concept could have more articulative power in our case. Thus, we see the need for a thorough review of the two concepts and their use in CSCW. Reviewing literature in CSCW conferences and journal, we found that in papers where both concepts are mentioned, the authors seem to have applied it to their respective cases without paying much attention to the details of the concept definitions.

In this paper we aim to make a concept review for both concepts, analyse the differences and similarities, and come up with some central issues that need to be discussed once a researcher chooses to apply the concepts of BOs or CMs.

In the rest of the paper, we present why the clarification of what is CMs and BOs can be beneficial, followed by a description of our methodology. Further, we present a detailed analysis of both concepts as they have been defined in the seminal papers: Boundary Objects in Star and Greisemer (1989) and Coordination Mechanisms in Schimdt and Simone (1996) [3, 4] and how the concepts have been interpreted by other authors. The purpose of this analysis is to provide a clarification of the concepts. Finally, we discuss six main issues that should be considered while discussing both concepts and how the concepts differ from each other in each of these issues.

2 Boundary Objects or Coordination Mechanisms?

The role of artefacts has been conceptualized in different ways within CSCW. In this paper we discuss what constitutes CMs and BOs, referring to the seminal definitions in [3] and [4] and what differentiates and unites these concepts. Both concepts have affiliations to symbolic interactionism and the work of Strauss [5], but provide different contributions to the understanding of artefacts. The usage of both concepts in analysing different cooperative work settings is not new. Many authors have used the concepts in their analysis, for example [6-10].

The curiosity sparked by the discussion of the usage of these concepts in our research project and increased after trying to find clarification in the literature. For example, reading about BOs in Trompette and Vick's paper [11:1]. In the introduction, they write: *"Susan L. Star and James R. Griesemer (Star and Griesemer, 1989) introduced the notion of boundary object on the basis of an ethnographical study of the coordination mechanisms of scientific work."* They use the "*coordination mechanisms*" two more times in their paper, without referencing to Schmid and Simone [4]. This makes us think that they use the term in its daily meaning, and not as a defined concept. However, within the field of CSCW both concepts have relevance, and thus, it is important to use them accurately in order to avoid confusion. Moreover, an illustration on how the choice of the concept can influence the analysis and conclusion are the papers [12, 13]. They both study emergency medical services, but while Kristensen, Kyng [13] focuses on analyzing the Common Information Space (CIS) and the coordination mechanisms in place, Zhang, Sarcevic [12] analyses the emergency services by considering the patient as the BO. This shows how the choice of the concept influences the analyses of a situation. Symon, Long [14] discuss work coordination in a hospital context. One of the objects used at the hospital is what they call the "report form". The authors describe the report form as a boundary object. However, the form coordinates the work among different actors who are in consensus with each other and influence each other's work. This is more in line with the definition of CMs. The lack of reflected use of the concepts reinforces the relevance of this paper.

Schmidt and Bannon's [4] paper was written after Star and Griensemer's [3] paper. Star and Griesemer's paper is not referenced at all by Schmid and Bannon. However, when Schmid and Bannon state that the concept of CMs is a generalisation for the many different ways in which the artefacts for coordination purposes has been used in different work domains, we find a reference to a paper of Bowker and Star [15]. So what Bowker and Star discuss as a BO in Schmidt and Bannon is inserted under the umbrella of CMs. However, there is no explicit discussion of the concepts side by side. Star revisited the concept of BOs in [16], without mentioning or referencing CM which by that time was defined and widely used in CSCW literature. Cabitza and Simone [17] in their paper on Computational Coordination Mechanism (CCM) refer to BOs and Boundary Infrastructure (referring to the book of Bowker and Star [27]) when they talk about categorical work. While they articulate the connection with the categorical work, they don't make any analysis or reflections on how the concept of BOs could relate to the CCMs that they present in the paper.

Zhang, Sarcevic [12] defines material and immaterial coordination mechanisms compounding a common information space (CIS). Within the material coordination mechanism, they list the common artefacts, which they identify as boundary objects [12].

Bossen and Markussen [6] dedicate a section to clarifying both concepts, BOs and CMs. They state that "*boundary object focuses on different social worlds (or communities of practices) and emphasizes how communication across these is achieved through standardization and formats that strike a balance between plasticity and robustness. On the other hand, the concept of a coordination mechanism focuses on how articulation and coordination of action among distributed actors within a social world are enabled and stipulated"* [6:620-621]. Moreover, they conclude that none of the concepts are good enough to explain the system they are analysing and the system actually shows characteristics of both. This is an example on how a clarification of the concepts can help the analysis of systems used in cooperative settings.

A similar discussion of both concepts is present in Hertzum [18] "Small-Scale Classification Schemes: A Field Study of Requirements Engineering". Both concepts are used to analyze and discuss the classification schemes. He states that *"while coordination mechanisms focus on how classification schemes enable cooperation among people pursuing a common goal, boundary objects embrace the implicit consequences of classification schemes in situations involving conflicting goals"* [18:35]. In a final analysis Hertzum [18] concludes that none of the concepts are able to describe the characteristics of classification schemas. Thus, he states that they become complementary in the analysis.

The cases presented above show that while the concepts have been used widely there is a need for clarification. In this paper we aim is to clarify the two concepts and highlight some issues that should be considered while discussing the concepts and how the concepts differ from each other in each of these issues.

3 Methodology

We did a systematic literature review in order to better understand the concept of coordination mechanisms and boundary objects, looking for how the concepts had been used, interpreted and amended in comparison to the seminal definition given by the authors that coined these terms. We used he following search terms for boundary objects: (“boundary object” OR ”boundary objects”) AND "Star", and for coordination mechanisms: ("coordination mechanism" OR “coordination mechanisms”) AND “Schmidt”. This decision for searching for articles that had the concept and the first author of the seminal paper, was made after a general literature search which showed that both concepts have been used in the literature as well as general terms, without referring to their definition in the seminal papers where they were coined as concepts. We decided to look for papers in ACM (which includes CHI, the CSCW and GROUP conferences, among others), the CSCW journal and ESCW conference as the main venues where the concepts have been used in the context of communication and cooperation in work settings.

We noticed that some of the main papers from Star herself were not published in these venues. Thus, we went back to Google Scholar to get a general overview of the most cited literature regarding the two concepts. We made an initial screening of the articles, and noticed that papers directly contributing with understanding or expanding/amending the concept of BOs and CMs had the name of the concepts in their titles. Thus, in Google Schoolar we serached for the concepts only on the title of the publications. The resulting list of publications was comprehensive. Hence, we decided to focus only on those papers that had a high number of citations. The result (after removing duplicates) was 185 articles to review for the concept of boundary objects and 81 articles to review for the concept of coordination mechanisms.

The initial screening of each article was based on the abstract and on a search of the respective concept within the article. We were looking for the following elements: Was the concept developed? What was considered a Boundary Object/Coordination Mechanism? Was the analysis of the concept aiming to influence the design of some sort of system? How was the concept used? In what context? Based on these elements we decided if the paper should be considered further. The main influence in the selection of articles to read further was if the concept has been analyzed or amended in the paper. Moreover, as the case that sparked our discussion was in healthcare, we decided to read papers with a healthcare context in order to see what was considered as BOs and CMs.

After the initial screening, 44 articles from BOs and 29 from CMs were selected for full reading. In the list of each concept, we found a group of articles that were the same, meaning had been using or at least referring to both concepts. The results of the literature review are included in the explanation of the concepts in the following section, and common usage of the concepts as described in the previous section.

To assure that no relevant paper was left out we did a Google Scholar search with the terms (“boundary objects” AND “coordination mechanisms”), resulting with no additional papers to be included in our review. We thus concluded that our paper selection was sufficient for the purpose of our analysis.

In the following section we present and analyze both concepts and reflect on both concepts vis a vis by defining six main issues to discuss for a better understanding of whether a given object is a CM or a BO**.**

4 Concepts presentation

In this section, we will discuss the concepts of BOs and CMs. Both have been relevant in CSCW in studying the cooperative work in organisations.

4.1 Boundary Objects

Leigh Star and Griesemer introduced the concept of BOs in their 1989 paper: "Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkley's Museum of Vertebrate Zoology, 1907-39" [3]. Since that seminal article, the concept has enjoyed a vigorous academic career, being deployed in different disciplinary fields [11, 19]. Different authors have used the concept of BOs as defined by Star and Griesemer [3] especially for descriptive, explanatory or analytical purposes in their research projects [20-24].

In this section, we state and discuss the concept of BOs as initially defined by Leigh Star in the seminal paper [3]. Further, we strengthen the concept understanding by referring to several other papers where Star revisits the concept of BOs [3, 16, 25-27] as well as how other authors have interpreted the Star and Griesemer [3] definition of the concept. Moreover, we present the main contributions in the literature that have attempted to amend the BOs concept.

Trompette and Vinck [11:9] state that *"the notion is sometimes employed in an anecdotal manner to refer to any artefact which is involved in coordination between actors or which is at the boundary of two worlds"*. The *"interpretive flexibility"* [16:602] that characterise the concept has been essential in deploying the concept in other disciplines.

In Leigh Star's and Griesemer's initial defininition of BOs [3], they write:

> *"This is an analytic concept of those scientific objects which both inhabit several intersecting social worlds and satisfy the informational requirements of each of them. Boundary objects are objects which are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use and become strongly structured in individual-site use. These objects may be abstract or concrete. They have different meanings in different social worlds, but their structure is common enough to more than one world to make them recognisable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds."* [3:393]

We now extract and analyze parts of the above definition more thoroughly.

The BOs are defined as scientific objects which inhabit intersecting social worlds. While initially defined as scientific objects which relate well to the context in which Star and Griesemer [3] did their study, in the second sentence the word "scientific" is not there, and BOs are defined merely as objects. The other part of the sentence builds on a concept defined by Strauss [28], social worlds. Strauss [28:119] defines social worlds as *"... an arena in which there is a kind of organization. Also, each is a "cultural area," its boundaries being" set neither by territory nor formal membership but by the limits of effective communication".* In her later work Star uses the concept of "communities of practice" along with social worlds. In Bowker and Star [27:294] they state "*We are all in this sense members of various social worlds—communities of practice-that conduct activities together*". The concept of communities of practice was coined by Lave and Wenger [29]. Wenger state that *"Communities of practice are formed by people who engage in the process of collective learning in a shared domain of human endeavour"* [24:1]. Communities of practice are based on the interest of people involved in learning collectively through partaking in a common practice. Thus, while a social world is a group of people connected through effective communication, in communities of practice that effective communication should be with the goal of learning a skill or practice. It is difficult to understand what Star meant by putting the two concepts along each other. However, in Bowker and Star [27] both concepts are used synonymously. Participation in a social world is considered as a daily learning process and in our view, this is a use of CoP that is too lose.

Moreover, the definition above states that BOs satisfy the informational requirements of each intersecting social world. The concept does not imply that the intersecting social worlds are necessarily collaborating in the sense of working toward a common goal [18]. BOs should be able not to infringe the autonomy of social worlds but at the same time facilitate communication between worlds. Referring to their case study Star and Griesemer [3] states that consensus is not always required in scientific works. In order to solve scientific problems, actors from different social worlds establish a mutual "modus operandi" [3, 28]. Thus, BOs allow communication among different social worlds even in the absence of consensus [30]. BOs serve as a means of translation among the social worlds, and each social world interprets it in their own way. Boundary objects are working arrangements, adjusted as needed. They *"are not imposed by one community, nor by appeal to outside standards"* [31:322]. BOs have the characteristic of bridging intersecting practices [32].

Star and Greisemer [3] define not only BOs but also methods standardization as the mean for communication among intersecting social worlds. Standardization is integral to the definition of BOs. It is due to this standardization that BOs are established and used. In Star and Greisemer [3] "method standardization" was initially established by one of the social worlds, by building on a common goal among all the involved social worlds. "*Preserving California's native fauna*" was the common goal shared by different social worlds and that was the incentive for the different social worlds to establish a common (standart) way to work together while still preserving their identity.

As state above in the definition *"boundary objects are plastic enough to adapt to local needs of these social worlds they are mediating but at the same time robust enough to be able to maintain a common identity across sites"[3:393]*. As Star refer to this in [26], BOs are *"weakly structured in common use but strongly structured in individual site use"*. Other authors have looked closer at the plasticity and robustness of BOs. For example, Fujimura emphasizes the need to augment the robustness rather than the plasticity of Boundary Objects, when these have to travel between diverse social worlds, and suggests the term 'standardized package' as an alternative to more robust boundary objects [21]. "Information objects and knowledge artefacts" are as other concepts developed to expand on the term and the rigidity of the boundary objects [33]

BOs, as defined above, may be abstract or concrete objects. Pennington [34] refer to BOs as material artefacts. Meanwhile, other research refer to more abstract and immaterial nature of BOs (e.g. [13]).

Moreover, BOs are not static. They change due to changes in involved social worlds or communities of practice [35, 36].

Two decades after the initial BO paper, Star writes an article titled "This is not a BO" [16]. She aims to clarify the concept that she and Greisemer defined and it is now mostly synonymised with interpretive flexibility. She sheds light on what boundary means to her: "*a shared space, where exactly that sense of here and there are confounded*" [16:602]. Moreover, she explains what object means for her: *"In common parlance, an object is a thing, a material entity composed of more or less well-structured stuff. In the term ''Boundary Objects'' I use the term object in both its computer science and pragmatist senses, as well as in the material sense. An object is something people (or, in computer science, other objects and programs) act toward and with. Its materiality derives from action, not from a sense of prefabricated stuff or ''thing''-ness*." [16:603]. Thus, Star claims materiality of the boundary objects but expanding the term of materiality into something that derives from actions and is not indispensably prefabricated stuff.

Star and Griesemer [3:410-411] list four types of BOs:

- Repositories – piles of objects indexed in a standard way.
- Ideal type or platonic objects – an object which is abstracted from all domains and can be vague.
- Terrain with coincidence boundaries – objects that have the same boundaries but a change in the internal compounding.
- Forms and labels – these are objects that serve as methods for common communication among disperse workgroups.

Bowker and Star [27] later added the classification system as an additional type of BOs.

In the definition above and the explanation, we notice that the rhetoric used considers BOs as concepts or material artefacts that have already emerged as a means of translation among social worlds. Thus, a wide range of research has been concerned with how these objects are actually created and manipulated to establish a shared understanding with different audiences [30, 37-39].

One of the main contributions comes from Lee [40] who coined the concept of boundary negotiating artifacts. Lee refers to those artefacts that are used to negotiate and develop understandings among distinct perspectives between social worlds. She states that "*artefacts and boundary objects are likely to be related and to vary in prevalence along a continuum from routine to non-routine work"* [40:314]. Lee suggests that the term Boundary Negotiating Artifacts might be better suited for projects that are non-routine and complex. Boundary Negotiating Artifacts are created when collaborators lack standardized processes and objects for collaboration (ibid.). However, the Boundary Negotiating Artifacts addressed by Lee can primarily be considered to be auxiliary artefacts, in the sense that they mediate work on a specific object, rather than being the object of work itself. They serve as mechanisms of pushing boundaries, and through negotiation build a common base of reference [41].

Other relevant concepts that refer or build on BOs will be listed below, as a way to open up the opportunity to the readers to search further how BOs are positioned regarding other relevant concepts in CSCW. However, these concepts are not part of the scope of the paper and will not be referred further.

"Assemblage" as a complex system that includes boundary objects, the practices around these objects (including organizational policies), work processes and coordination mechanisms within these objects, and special functions for designated groups [42].

Bowker and Star [27] introduce the concept of boundary infrastructures. Boundary infrastructures serve multiple communities of practice simultaneously and often contain a selection of boundary objects. Boundary infrastructures are developed over the course of time to provide stable support for collaborative activities.

Boundary zones, coined by [43]. It refers to the alignment of interests among stakeholders. It doesn't necessarily include boundary objects. It is the area where the social worlds interact, and the continuous collaboration of the social worlds can result in boundary objects or boundary infrastructures.

Boundary specifying objects - Pennington [34] defines two classes of boundary objects: 1) those that specify viewpoints and fully mediate their interaction which she calls boundary specifying objects, and 2) those that negotiate interaction between viewpoints on which she refers to the concept of boundary negotiation objects. Thus, she refers to boundary objects as an umbrella term including both boundary specifying objects and boundary negotiating objects. She states that the concept "boundary object" should refer to any artifact that is used to cross community boundaries, whether it is used for negotiation, for specification, or for any other boundary crossing process. Regardless of how it is used, it is an artifact at the boundary between communities. Moreover, the seminal definition of BOs is considered by Pennington as a boundary specifying object.

4.2 Coordination Mechanisms

The initial definition on CMs is presented by Simone, Divitin and Schmidt [44]. However, most subsequent use of the concept references "Toward a Conceptual Foundation of CSCW Systems Design" by Schcmidt and Simone as the seminal publication of the concept [4:165-166]. They define CMs as:

"a specific organisational construct, consisting of a coordinative protocol imprinted upon a distinct artefact, which, in the context of a certain cooperative work arrangement, stipulates and mediates the articulation of cooperative work to reduce the complexity of articulation work of that arrangement."

One of the main pillars of the concept is the articulation of cooperative work. Thus, making cooperative work and articulation work two important concepts to explain and understand CMs. *"Cooperative work is constituted by multiple interdependent actors, which interact through changing the state of a common field of work*" [4:158]. In order to restrain the distributed nature of complexity interdependent activities, the actors need to articulate the distributed work [4].

In cooperative work, there are individual interdependent activities, which are distributed in time and space. The actors who cooperate with each other are "*semiautonomous in terms of the different circumstances they are faced with in their work as well as in terms of their strategies, heuristics, perspectives, goals, motives, etc.*" [4:158]. The change in state of one's individual field of work consequently changes the common field work where others also operate. Thus, to avoid confusion, there is a need to articulate the individual and still interdependent activities (which is how articulation work has been defined by Strauss [5]). Articulation work becomes complex in really interdependent and complicated work arrangements. Thus, to reduce the complexity of articulation work specialised artefacts are needed. This is where the CMs enter the scene.

In the definition, we notice that two elements constitute a CM. One is the coordinative protocol which denotes procedures and conventions stipulating the articulation of interdependent distributed activities and ways of achieving cooperation among different actors. The other is the artefact, which is a distinct and persistent symbolic construct where the protocol is imprinted and objectified. It has an ad-hoc nature [4].
Cabitza and Simone [17] in their paper on Computational Coordination Mechanisms state that the term coordination mechanism can be interpreted, in the most general terms, as any kind of construct that is at least in principle computable and whose aim is to organize activities performed by a group of actors that are called to cooperate for some purpose or reason.

CMs are rooted in symbolic interactionism. Thus, they are a valuable resource for situational action. They provide actors with some predefined procedures that they can act upon. In this way it reduces the range of possibilities for action by identifying a valid and yet limited set of options for coordinative action in any given situation [4]. CMs can be weak stipulations, which serve more as a guideline of how actors should behave, or they can be a strong stipulation in the role of a script where the actors get a set of instructions on how to behave in a cooperative setting in order to get the job done [4]. However, the artifactually imprinted protocols do not represent what actually happens in the work setting, and there will always be a situation which will go beyond the boundaries of a CM [4]. It is important for the CMs to be flexible enough that it allows the deviations of workflow from the protocol, without being totally discarded.

Referring to the definition of a CMs presented above, the CMs is called so only in the case of an artifactually imprinted protocol. The artefact is central in denoting the changes in the protocol. It may be the information in the artefact itself or its location etc. that might constitute the change in the protocol and consequently the change in the state of work. In most work situations, there will be more than one CM. They might interrelate with each other and influence the execution of each other.

Finally, it is important to understand what the artefact is in a CM. It can be a paper artefact. a kanban system [4], or a computational artefact [17].

The concept of the coordination mechanism, as defined, clearly describes material artefacts. This approach has been considered to be narrow by Bossen in [7], who emphasizes that organizational structures and divisions of labour also facilitate coordination of work since they explicate who does what and when. Thus, Bossen uses the term immaterial mechanisms of interaction for these other constructs which facilitate articulation of cooperative work [7].

Ordering systems are considered a special case of coordination mechanisms defined as the work that helps people create an order from a vast collection of items. However, Cabitza and Simone [17] state that the genesis of ordering system is described by the concept of categorical work presented in Bowker and Star [27] and their work on the classification schemas.

Some important related concepts with coordination mechanism are:

Awareness – "*while the property of awareness is conceptually distinct, it is brought about through accountable acts of communication and the operation of some types of coordination mechanism*" [45:533]; B

Common information spaces – A concept applied to *"examine how understanding of shared information or objects is constructed in particular settings"* [12:935].

5 Discussion

In this section, we will present six issues to discuss and consider when deciding to make use of the concepts of Boundary Objects or Coordination Mechanisms. Table 1 is a summary of the terms of discussion elaborated below.

Table 1. Summary of the discussion.

BOUNDARY OBJECTS	COORDINATION MECHANISMS
Helps the translation of information among Social Worlds/Communities of practice	Facilitates the articulation work for cooperative work among Actors
The social world preserve autonomy by pooling in the intersection only the necessary information • Enhance communication but without interfering in each social world activities • The changes made in one social world do not necessarily trigger actions in the others	Semi-autonomous actors • The activities of actors will change based on their cooperation • CM will serve as the incentive of changing the status of an activity happening in a cooperative work setting, thus triggering other activities for other actors
Social worlds do not need to achieve consensus regarding the individual goals of each social world, but they should agree on the effort put in translation and cooperation among the intersection social worlds	The consensus is required among actors in order to get the work finished

It may be an abstract concept or a concrete artefact	Imprinted coordination protocols - constituted by the coordination protocol AND the artefact
Weakly structured in common use, strongly structured in individual use	Strongly structured in common use

Who is involved? BOs are defined in the intersection of social worlds or communities of practice, while CMs aim to support the articulation of cooperative work among different actors. Thus, the actors in CMs could belong to the same social world as Bossen and Markussen [6] state or could be used to coordinate work among actors that belong to different social worlds or communities of practice.

In the case of CMs the focus are actors that cooperate for a common work goal. In BOs the reference to social worlds and later communities of practice creates difficulties in envisioning the role of the concept due to the flexibility in interpreting what can be considered a social world. In Bowker and Star [27:294] social worlds and communities of practice have been used as synonyms. Wenger defines communities of practice as collaborative learning communities by focusing on improving practice [24]. While communities of practice are focused on collaborative learning, social worlds is a more general term. The aim in this paper is not trying to define social worlds or communities of practice and when is the correct way of using them. However, we want to clarify that when researcher uses the BOs concept they should have a clear understanding of their social worlds or communities of practice. In this way, their analysis of the objects that sit in the intersection of these social worlds or communities of practice will be more rigorous.

Application. Even though Star in [16] restates the focus of BOs in the work setting, the usage of the social world as a term borrowed by Strauss or communities of practice from Wenger gives it a more general spectrum of applications than the clear positioning of CMs within work settings and cooperative work.

If we narrowly analyze the definition of BOs and the terminology used, we can relate BOs with scientific collaboration settings where researchers have different research interests. Leigh Star initially defines BOs as scientific objects. In the case of the Museum of Vertebrate Zoology [3] she also refers to the attempt to create scientific knowledge. Moreover, communities of practice focus on learning, and might intersect with other communities of practice in order to help to achieve some information that can increase their knowledge. Based on this analysis we could argue that BOs can be found more in cross-disciplinary research and are objects aimed to facilitate scientific collaboration. However, Star also defines BOs as objects which intersect many social worlds. This definition adds interpretive flexibility to the concept , and Leigh Star [16] emphasizes the interpretive flexibility in her last paper regarding BOs. The conclusion is that we find CMs in cooperative work settings and BOs in a broader set of situations, perhaps with a special focus in scientific work.

The relation between actors and activities. In CMs actors and their activities are semi-autonomous. The activities of one actor could change the common work space and consequently change the state of the work space for the other actors. Meanwhile, BOs facilitate the communication and translation of information between social worlds without infringing their autonomy. Only those parts of the work which are essential for maintaining coherent information across the social worlds are pooled in the intersection. The work of one social world does not stop the workflow in the other social worlds. However, Star and Greisemer state that "*Each world is willing - for a price - to grant autonomy to the museum and to conform to Grinnell's information-gathering standards.*" [3:407]. Thus, by using BOs, the actors keep their autonomy focusing on the ability to pursue the individual goals in each social world, whilst still contributing towards a common shared goal or for a price. With CMs people need to work together to make the job done. They don't choose to do so as part of a bigger goal; the do so because that is the only way for having the work finished.

BOs are used to support the communication between different worlds but without radically changing the routine activities that happen in each of the worlds. The social worlds preserve autonomy in their activities. Maintaining BOs can be a small extra part of their activities that they do due to the common goal. The modification made in the information that BOs carry between social worlds will be visible for the other social worlds. However, it will not trigger any specific activity in another social world.

Meanwhile, CMs can be weak stipulations of cooperative protocols, which might serve as guidelines for its actors, or it can be strong stipulations where actors have to follow the instruction to get the work done. A CM introduced in a working place will influence and change the activities of each actor in order to comply with the coordinated work. The protocol associated with a CM will define the working procedures and how each of the actors works with the CMs. CM will serve as the incentive of changing the status of an activity happening in a cooperative work setting. It might trigger another actor to initiate an activity.

Achieving Consensus. Star and Griesemer [3] states that when using BOs different social worlds do not need to achieve consensus among each other. They are interdependent, but they might enter in collaboration even without a consensus by establishing a modus operandi. Reflecting on these issues we would argue that social worlds do not need to have a consensus regarding indiviadual goals in each social worlds, but they need to create a consensus on how the translation and collaboration with each other will be. Lee [40] defined Boundary Negotiating Artifacts as a concept to refer to objects that were used in the phase where social worlds negotiate boundaries and consensus. That can lead to established BOs. Instead, establishing CMs require the actors to be in consensus first regarding the protocol and how the work will be done, and then how this work could be facilitated through CMs.

Materiality. Based on the definition of BOs in Star and Griesemer [3], boundary objects may be abstract terms or concrete objects. That is as well how the BOs have been used in the literature both as an abstract and concrete object. Moreover, Star tries to shed light on this part of the concept in [16], saying that an object is something people act toward and with and does not relate to it ting-ness. Instead, a CM cannot be a concept. It is an imprinted coordinative protocol, constituted by the coordination protocol AND the artefact. Thus, BOs create more flexibility in materiality than CMs.

Structure. BOs as shown in the definition presented above in the section Concepts Presentation, "*are weakly structured in common use but strongly structured in individual use"[3:393]*. They are robust enough to be recognized among social worlds and flexible enough to be used in each of the social worlds. While they have a vague definition on a larger scale, once applied in the specific social world, it gets its well-defined shape [26]. The BO is then used individually, without intervening with work in other social worlds. This is illustrated by the example of the field note form used by Star, which shows that the forms are understandable among social worlds, but they are used specifically in each of the worlds for supporting internal social world activities. This is different with CMs. The changes that one actor does in a CM are reflected in the common work field and would influence the work of others. Thus, it needs to be strongly structured in common use.

6 Conclusion

This paper aims to clarify the concepts of BOs and CMs. We present a thorough analysis of each of the concepts, and we discuss them side by side by emphasizing six issues that a researcher could refer to before using the concepts. The issues have been analyzed in detail above. It would be beneficial for the researchers to discuss these issues and be clear what each of them pertain in their case. Hence, they can use the concepts in an adequate way and make use further of the strength of each of the concepts in analysis.

While the above-mentioned issues help in clarifying if the researcher refers to a BO or a CM the analysis could be influenced by the scope and scale of the analysis and from which perspective the analysis is conducted. Star [16], while discussing what is not a Boundary Object defines scope and scale as two main elements in influencing what could be considered or not a boundary object. The aim for future work is to apply the concept analysis in a practical case and discuss how they might be interrelated with each other.

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