“We are just sitting here”: patient participation for elderly with dementia.

A qualitative study investigating the implementation of patient participation by healthcare professionals in a Dutch residential care home for elderly with dementia.

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Declaration of Oath

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26.06.2020	26.06.20
date and signature of student	date and signature of supervisor

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So, finally I can write this page which means I am at the end of this long, long, but very exciting journey. But before delivering this thesis, I would like to express my appreciation.

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Abstract

Institutionalized elderly with dementia should, regardless of their reduced mental capacity, be involved in their own care. Elderly, chronically ill patients are often found vulnerable and limited in their ability to participate. Ample research is available on patient participation; however, the enhancement of it has mostly been studied in hospital settings, not in nursing homes. This research focuses on the implementation of patient participation in the context of dementia care. In order to provide an answer on the following research question: “How do healthcare professionals influence patient participation in a specialized dementia care unit in a Dutch nursing home?”, a case study is performed. This is facilitated by semi-structured interviews among eleven health care professionals working in a specialized dementia care unit. Based on the literature, four attributes of patient participation were addressed, and the influence of health care professionals’ attitude and behaviour was analysed. The findings showed that health care professionals have a great influence on opportunities for residents’ participation. Especially in dementia care, residents are dependent on health care professionals’ guidance, willingness and ability. Therefore, health care professionals need to observe, sense and know residents to accommodate their wishes and needs. Picking up signals as well as valuing residents as equal partners were strong facilitators to involve dementia residents in their care. The most critical hindrances were residents’ negative attitude, absence of knowledge on dementia care, task-oriented nursing labour and lack of self-reflection. Establishing relationships was a natural consequence of caring for dementia residents, which is strengthened by both verbal and non-verbal communication and underlying values, such as empathy and trust. This research shows the ability of healthcare professionals to facilitate patient participation regardless of residents’ cognitive impairment. Through an awareness of the hindering and facilitator factors together with critically, reflective thinking of healthcare professionals, patient participation can be enhanced within dementia care.

Keywords*: patient participation; elderly with dementia; empowerment; residential care; health care professionals; attitude; specialized dementia care units; the Netherlands.*

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Chapter 1 - Introduction

The first chapter provides the motivation for this research on patient participation. First, the problem underlying this research will be presented and analysed. Secondly, the research objective, questions and approach will be outlined. The theoretical and practical relevance will be touched on accordingly. Lastly, the outline of this study will be presented.

1.1 Background

Health care professionals are essential to create an environment in which patients feel able to participate (Tobiano, Bucknall, Marshall, Guinane & Chaboyer, 2015). Physical activity and engagement in meaningful activity reduces neuropsychiatric symptoms and improves health, well-being and quality of life for elderly (Christofoletti et al., 2011). Furthermore, patient participation is essential to provide high-quality healthcare (Phillips, Street, & Haesler, 2014). Evidence has shown that it enhances the decision-making process, improves the care of chronic illnesses and improves patient adherence to healthcare practices (Phillips et al., 2014; Longtin et al., 2010). Hence, to improve safety and outcomes related to quality of care participation of patients is important. Despite an inconsistent definition of patient participation, it implies an active involvement of the patient in their own healthcare processes (Cahill, 1996; World Health Organization, 1978; Phillips et al., 2014). Participation, however, is a complex concept and often a challenge for both healthcare personnel and patients (Tutton, 2005). Especially in the care for vulnerable patient groups, such as elderly with chronic diseases (Efraimsson, Sandman, Hydén, & Rasmussen, 2004). Moreover, a better understanding is required on the ability of elderly with dementia to participate in their own care (Helgesen, Larsson & Athlin, 2014).

Dementia is the umbrella term of several diseases that affect memory and other cognitive abilities and behaviour that significantly impairs someone's daily living (National Institute on Aging, 2017). In most cases people with dementia are placed into care homes as their needs become too complex or too intensive for relatives to remain at home (Hancock, Woods, Challis, & Orrell, 2006). In 2019, 280.000 Dutch citizens had dementia of which 80.000 received inpatient care in mostly nursing homes (Alzheimer Netherlands, 2019). The growing aging population characterized by complex multimorbidity is a threat to the Dutch healthcare system (Hilderink & Verschuuren, 2018; Rijksinstituut voor Volksgezondheid en Milieu, 2018). With the rising cost of care homes and the imposed financial implications it is necessary to provide high quality of care and to minimize distress. Scholars recognized patient participation as a component to achieve high quality of care, such as better treatment results (Sainio, Lauri, & Eriksson, 2001), reduced mortality and improved functional status (Phillips et al., 2014).

Application of patient participation in dementia care is perceived as a complex phenomenon as it often requires a reasonable cognitive level and ability to understand instructions (Garcia-Ptacek, Dahlrup, Edlund, Wijk, & Eriksdotter, 2019; Helgesen et al., 2014). Nonetheless, one should not forget the existing competences of elderly with dementia and to make care more tailored to their needs (Lyttle & Ryan, 2010; Penney & Wellard, 2007). To be able to participate in their own care, dementia residents often rely on the healthcare professionals (Helgesen et al., 2014). Staff have the opportunity to create and improve a meaningful life for them and to secure a good experience in care (National Clinical Guideline Centre (UK), 2012). They are the closest to dementia residents and can offer tailored, appropriate care and, as such, patient participation is at the heart of nursing practice (Sahlsten, Larsson, Sjöström, & Plos, 2008).

1.2 Research area

1.2.1 Research objective

As outlined above, many researchers (Longtin et al., 2010; Philips et al., 2014; Sahlsten et al., 2008; Tutton, 2005) highlighted the importance of patient participation to empower patients and to improve quality and organization of care. Moreover, the crucial role of healthcare professionals in relation to patient participation has also been acknowledged (Helgesen et al., 2014; Tobiano et al., 2015). As research on patient participation, however, has mostly been conducted within hospitals (Sahlsten et al., 2008; Tutton, 2005), little research has been done on the implementation of patient participation within specialized dementia care homes to empower dementia residents and to improve their quality of care.

To study patient participation in the provision of care for elderly with dementia, a study has been conducted at a Dutch nursing home. The healthcare professionals working at the specialized dementia department within this nursing home are interviewed about dementia care. This study gives insights in the perspectives of health care professionals, such as nurses and care assistants. Therefore, this research is based on their views and experiences. This knowledge is important to ensure improvements in care of chronic illnesses (Longtin et al., 2010) and the empowerment of dementia residents in their own healthcare processes (Halskov, Lauridsen, & Hoffman, 2017). The aim of this thesis is: “To provide empirical evidence of how healthcare professionals influence patient participation in residential care for elderly with dementia, by exploring and studying facilitating and hindering factors as well as the influence of healthcare professionals’ attitude and behaviour in practice through qualitative research methods.”

1.2.2 Research questions

Drawing on the background, the relevance of research on participation of elderly with dementia and the objective of this study, the following research question is defined:

> *"How do health care professionals influence patient participation in a specialized dementia care unit in a Dutch nursing home?".*

Within previous research (Sahlsten et al., 2008; Tutton, 2005) various elements of patient participation have been suggested on how patient participation can be enacted. For example, the extent to which patient participation can be satisfied depends on the power or control nurses possess (Sahlsten et al., 2008). Healthcare professionals working with elderly additionally need to develop a deeper understanding on patient participation. In line with the urgency for research on dementia care and in order to provide an answer to the research question, the following supplementary research questions have been formulated:

1. *Which facilitating and hindering factors do health care professionals encounter in the implementation of patient participation?*
2. *How do health care professionals influence the implementation of patient participation?*

1.2.3 Research approach

A qualitative study aims to provide an answer on the previously mentioned research questions. In this thesis, the theoretical framework which is based on the theories of Tutton (2005) and Sahlsten et al. (2008), will serve as the starting point to validate the elements of patient participation in practice. Furthermore, this study will elaborate on studies of Penny & Wellard (2007), Tobiano et al. 2015 and Helgesen et al. (2014), with regard to the stimulation of patient participation by healthcare professionals in the caring for older people, especially elderly with dementia. Qualitative research methods provide insights in the experience, meaning and perspective, from the standpoint of the participant (Hammarberg, Kirkman, & De Lacey, 2016). By conducting in-depth, semi-structured interviews the researcher facilitates in-depth insights on the perspectives of participants' and explores these issues in practice (Boyce & Neale, 2006). More specifically, nurses have a unique perspective on the caregiving for elderly with dementia care and can facilitate or hinder residents to participate (Helgesen et al., 2014; Tobiano et al., 2015). To fully capture the role of those professionals with regards to patient participation in dementia care, it seems appropriate to collect personal experiences. Therefore, semi-structured, open-ended interviews are conducted within a single case study, as data has been gathered at one specialized dementia care unit of a Dutch nursing home. A case study design enables the researcher to conduct an in-depth description of the phenomena in practice.

1.3 Relevance of this research

This study has relevance both for the scientific community as well as policy makers, dementia patients and their carers.

1.3.1 Scientific relevance

There is now plentiful research on participation of patients in care and treatment decisions (Longtin et al., 2010; Sainio et al., 2001; Sainio & Lauri, 2003; Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014). However, present studies on patient participation were mainly constrained to hospital care (e.g., Ekman et al., 2012; Hansson et al., 2016; Tobiano et al., 2015; Tutton, 2005; Van Belle et al., 2018). Additionally, the importance of health care professionals in order to optimize patient participation in hospital settings has been researched (Efraimsson et al., 2004; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007; Sahlsten, Larsson, Sjöström, & Plos, 2009; Sainio et al., 2001; Tutton, 2005).

Nonetheless, more research is required to validate the elements of patient participation in practice (Sahlsten et al., 2008) as well as to obtain a better understanding of this phenomenon in the specialized dementia care (Helgesen et al., 2014). As most research solely focuses on hospital care, there is a lack of empirical research on patient participation in dementia care (Helgesen et al., 2014). Nonetheless, previous research shows the importance of stimulating older people with chronic diseases in their own care in order to deliver high standard of care (Halskov et al., 2017; Lyttle & Ryan, 2010).

This research contributes to theory by studying the implementation of attributes of patient participation in dementia care and broadening the understanding of how healthcare professionals can influence and enhance patient participation within a specialized dementia unit. Helgesen et al. (2014) suggested to increase awareness among dementia caregivers to promote patient participation, which implies the need for research in this specific area. Care for elder chronically ill patients should empower them irrespective of their dependency (Halskov et al., 2017). Patient cognition is a crucial factor for patient participation (Tobiano et al., 2015), hence healthcare professionals might encounter this as a challenge in caring for elderly with dementia. Therefore, this research aims to attribute to scientific knowledge on patient participation in specialized dementia units rather than hospital care as well as the influence of healthcare professionals in the implementation of participating dementia residents.

1.3.2 Policy relevance

As dementia care has significant social and economic implications for the Dutch society, it is important to elaborate on those accordingly (Van Bussel, 2017). More than 280.000 Dutch citizens have dementia, and this is expected to become the leading cause of death in the Netherlands by 2040 (Alzheimer Nederland, 2020; Hilderink & Verschuuren, 2018). Every hour five additional Dutch citizens have to deal with dementia, according to the facts and figures presented by Alzheimer Netherlands (2019). In 2017, Dutch healthcare costs related to dementia were 9.3 billion, which accounts to 9.5% of the total healthcare costs in the Netherlands (Alzheimer Netherlands, 2019). Dementia is a common disease with the highest medical expenses. 60% of the cost on healthcare were spend on inpatient care (mostly nursing homes). The Dutch Ministry emphasized a call for action in respect of the elderly and their complex health-related problems. The growing ageing population implies an increase in chronic patients with osteoarthritis, diabetes and dementia (Hilderink & Verschuuren, 2018). To avoid putting excessive pressure on the Dutch healthcare system, patients need the ability to participate in their own care.

Secondly, it is important for policy makers within nursing homes to focus on the existing capabilities of elderly with dementia. Although dementia patients suffer from cognitive impairment that can compromise social functioning (Hugo & Ganguli, 2014), they still have the physical capabilities to attend activities (Cohen-Mansfield, Thein, Dakheel-Ali, & Marx, 2010). Yet daytime activities are one of the most common unmet needs of dementia residents (Hancock et al., 2006). It is for this reason, important to establish and implement policies on meaningful activities. As such, dementia residents will feel encouraged by healthcare professionals to participate.

Lastly, the results of this study can provide insights for the nursing home with regards to the experienced facilitators and barriers to patient participation in the specific unit. In this way, the professionals can deepen their understanding of patient participation and their importance in this process likewise. Hence, this study can provide insights into the organisation of patient-centred care within the specialized unit as well as in the nursing home.

1.4 Outline

To study the implementation of patient participation by healthcare personnel in care for elderly patients with dementia, it is necessary to introduce and clarify the most important concepts. The theoretical concepts and frameworks will be presented in chapter two. Hereafter, chapter three elaborates on the research methodology. The main results of this qualitative research will be elaborated on in chapter four. Finally, chapter five will present the discussion and conclusion of this research. In this last chapter, the main findings, and limitations will be discussed as well as implications and recommendations for future studies.

Chapter 2 -Theoretical background

Studies of patient participation show a lack of consistency regarding definition and processes (Tutton, 2005; Phillips et al., 2014). The theoretical roots of patient participation will be discussed in this chapter to show how patient participation can be positioned within the broader context of patient-centred care and to specify prior research findings that underpin this study. Hereafter, the significance of patient participation for elderly will be elaborated on followed by influence of healthcare professionals on the dynamic process of participation. Subsequently, patient participation is conceptualized according to two theoretical perspectives, followed by the formulation of different elements of this concept. This chapter concludes with the theoretical framework in which the perspectives of Tutton (2005) and Sahlsten et al. (2008) will be combined to perform the analysis.

2.1 Patient-centred care: the provision of healthcare

Over the last years, a patient-centred approach is gaining ground in the delivery of healthcare (Delaney, 2018). Patient-centred care (PCC) can be defined as *"providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions"* (Institute of Medicine, 2001, p. 3). This approach steps away from the 'doctor knows best' approach and tries to make care more tailored to the needs of patients (Kuipers, Cramm, & Nieboer, 2019). PCC requires the engagement of diverse providers in the continuum of healthcare provision (Heeringa et al., 2020; Levesque, Harris, & Russell, 2013). This shift calls for better integration and coordination of health care which indicates an emerging focus on chronic disease management.

The primary principles of PCC support autonomy and the right to self-determination (Delaney, 2018). A synthesis of prior literature on patient-centred care, defined three common core elements: patient-centred care including the relationship between the patient and the health professional, the context where the care is delivered and patient participation and involvement (Kitson, Marshall, Bassett, & Zeitz, 2013; Tobiano et al., 2015). In this view, today's partnership between patients and healthcare professionals encourages patients to actively participate (Eldh, 2019). PCC aims to foster better working partnerships which in turn provides insights to health care professionals to tailor customers' needs (Delaney, 2018).

Initially, patient participation originated from the decision-making process and has been discussed in situations as bedside reporting (Timonen & Sihvonen, 2000), discharge planning (Efraimsson et al., 2004) and decision-making in treatment and care (Sainio & Lauri, 2003). Now it has been successfully applied to other areas of patient care such as the management of chronic illnesses (Longtin et al., 2010). Despite the lack of a clear definition of patient participation, various terms are related to this concept, for example: patient involvement, collaboration, empowerment, partnership, and patient-centred care (Phillips et al., 2014; Longtin et al., 2010).

2.2 Patient involvement in healthcare

The literature on patient participation mainly draws on two theoretical views. On the one hand, Cahill (1996) argues that there is a hierarchical relationship between the three concepts involvement, participation and partnership. In this hierarchy, patient involvement is a prerequisite to achieve patient participation, which in turn is a prerequisite for patient partnership (Gopee & Galloway, 2017, p. 207).

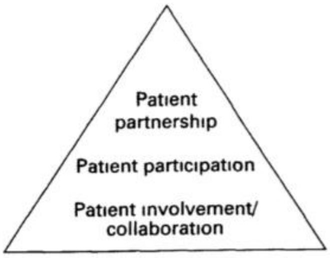


Figure 1. The hierarchical relationship between the concepts (Cahill, 1996, p.567).

Participation requires an active involvement from the patient. Five attributes of the concept of patient participation within the context of nursing practices were identified by Cahill (1996). To achieve patient participation, the following attributes are required: a relationship between healthcare professional and the patient, the narrowing down of information and knowledge gaps between healthcare professional and the patient, the surrendering of power/control by the healthcare professional, the engagement in meaningful activities during some phases of the healthcare process and a positive benefit associated with the intellectual and/or physical activity. Although Cahill (1996) concluded that patient participation remains a complex and sophisticated concept as it is a matter of perpetual consensus, it is extremely important to nursing practices. There is a need to develop the concept analysis of patient participation when new knowledge and experiences becomes available (Cahill, 1996).

The work of Cahill (1996) has as such led to further development of the concept of patient participation by Sahlsten et al. (2008). Their concept analysis aimed to identify and explore the attributes of the concept and to clarify the meaning of patient participation within the context of nursing practices. Next to that, it illuminates the role and requirements of the nurse in relation to patient participation. As per Sahlsten et al.'s (2008) concept analysis, four attributes were defined within the context of nursing practice including: an established relationship, a surrendering of some power or control by the nurse, shared information and knowledge, and active mutual engagement in intellectual and/or physical activities.

When comparing the results of Cahill's (1996) concept analysis with Sahlsten et al.'s (2008), the defining attributes have remained the same but the latter one provided more detailed attributes. Especially in the case of the nurse, valuing the patient as equal as well as handing over control to the patient is required to create a participation setting. Although both theoretical frameworks can be used as useful guides, the approaches lack an explicit validation phase to verify the presence and existence of the proposed defined attributes of patient participation in practice (Sahlsten et al., 2008).

Tutton (2005), on the other hand, refers to patient participation as a dynamic process, rather than a hierarchy of decision-making. Participation is viewed as a dynamic process that changes over time, which occurs in the context of care giving. Moreover, it is integral to the work of nurses and (informal) caregivers. The dynamicity of patient participation is at the core of the research conducted by Sahlsten et al. (2007). The dynamic nurse-patient interaction process is shaped by 'mutuality in negotiation'. This mutuality includes the exchange and co-operation between nurse and patient, which is characterized by intimacy, contact and understanding. Negotiation involves a *"continuous dynamic process of communication, evaluation and change"* (Tutton, 2005, p. 147). Within her conceptualization, Tutton (2005) distinguishes four elements that shape the process of participation in a hospital setting for older people, which are: facilitation, partnerships, understanding the person, and emotional work. Decisions taken by nurses can eliminate the power of patients but can become participatory through the context of these four elements. Opportunities for patients' participation in care can be created through nurses' reflection on their daily work and an increased awareness of participation and the implications of nurses' actions (Tutton, 2005; Helgesen et al. 2014). The work of Tutton (2005) led to much more research on the importance of a relationship and a dynamic interaction between the nurse and the patient (e.g., Soleimani, Rafii, & Seyedfatemi, 2010; Lindberg, Persson, Hörberg, & Ekebergh, 2013; Tobiano et al., 2015; Kolovos, Kaitelidou, Lemonidou, Sachlas, & Sourtzi, 2016; Saei & Rahimi, 2017; Van Belle et al., 2018; Guldager, Willis, Larsen, & Poulsen, 2019).

2.3 The need for older people to participate in dementia care setting

Iliffe et al. (2004) identified the five most common domains of unmet needs of older people: physical ability, senses, incontinence, memory and emotional distress. For dementia residents, the most common unmet needs are lack of company, psychological distress, daytime activities, senses and memory (Hancock et al., 2006). The nature of needs differs across the stages of elderly with dementia, which suggests that interventions and effective care need to be tailored according to this specificity and complexity (Ferreira, Martins, Dias, & Fernandes, 2016). Regardless of age, sex or race, all patients should be able to participate in their own care and to take part in decisions about their own health and healthcare (World Health Organization, 2015). The degree to which someone actually wishes to participate in their own care may vary, but advanced age cannot form the basis of discrimination (Holmqvist & James, 2019).

Although there is much known about the social and economic impact of dementia, little is known about how healthcare professionals can facilitate patient participation in dementia care settings (Hilderink & Verschuuren, 2018; Alzheimer Netherlands, 2019). With the increasing threat to global health, the World Health Organization called for action at international and national levels to promote dementia as a public health priority (World Health Organization, 2013; 2017). Currently there is no treatment available to cure dementia which emphasizes the necessity of providing information to overcome stigmas and optimize physical health, activity, cognition and well-being of those with dementia to increase their quality of life (World Health Organization, 2019). Notwithstanding their reduced mental capacity and the progression of dementia, dementia patients still have the resources to properly deal with parts of their lives (Lillekroken, Hauge, & Slettebø, 2015). Prior research on perspectives of elderly patients on patient involvement in home care shows that the organization of care should empower elderly, chronically ill patients even if they are in a dependent position (Halskov et al., 2017).

Patient empowerment was introduced to allow patients to play an active part in the decision-making process about their health and quality of life (Castro, van Regenmortel, Vanhaecht, Sermeus, & van Hecke, 2016). Patient-centred care, patient involvement, and patient participation emphasize the responsibility and key role of patients in their own health management. Older people seem particularly vulnerable in the area of autonomy, in which personnel retain a controlling position in staff-patient interactions (Tutton, 2005). Elderly with chronical health conditions are often described as limited in their ability to participate (Efraimsson et al., 2004). There is a need for older people to be more involved in the decision making at all levels (Lyttle & Ryan, 2010). Involving older people in their care, enables them to determine their needs in order to foster the translation of required care and finally to set the desirable outcomes (Andrews, Manthorpe, & Watson, 2004). This involves among other things, consultation to gather older people’s view and participation in the decision-making process. This participation of older people in their own care is important, even when institutionalized (Barkay & Tabak, 2002; Lyttle & Ryan, 2010). Moreover, engagement of elderly in activities supports their independence, creates the opportunity to be listened to and it supports the provision of clear information about treatment plans (Penney & Wellard, 2007).

Besides the positive influence of patient participation on the organization of care (Longtin et al., 2010; Phillips et al., 2014) it is likely to increase the quality of care likewise. Patient participation is currently linked to high-quality healthcare, such as a reduction in mortality and improved functional status (Phillips et al., 2014). Additionally, literature on PCC generally portrays a positive empirical relationship between participation and patient outcomes (Cramm & Nieboer, 2016; Kuipers et al., 2019) as it is likely to result in increased satisfaction with received care (Williams, Freedman, & Deci, 1998; Henderson, 2000) and better treatment results (Sainio et al., 2001).

2.3.1 The role of nurses

The role of nurses in the process of patient participation is crucial yet challenging (Tobiano et al., 2015). First of all, nurses recognize their importance in facilitating patient participation in the context of a medical ward (Tobiano et al., 2015). They view themselves as supportive to both physical and verbal participation. Moreover, nurses acknowledged the positive influence of patient participation as it decreases the vulnerability of patients (Henderson, 2000). Nurses can create a climate in which patients feel comfortable to participate through their humour, introductions and communication (Tobiano et al., 2015). Verbal motivation and the provision of information are ways nurses can establish a relationship with the patient that in turn can facilitate and engage participation in care. The nurse's role in adopting participation remains complex, having to balance patients' needs and risks.

In general, nurses' attitude determines patient participation in several ways (Henderson, 2000; Helgesen, Larsson, & Athlin, 2010). First, healthcare professionals need to have a positive attitude towards patient participation to facilitate this process (Angel & Frederiksen, 2015). As such, patients can feel more informed and empowered (Allen, 2000; Kettunen, Poskiparta, & Karhila, 2003) when health care professionals appear to have more empathy and know how to communicate better (Tempfer & Nowak, 2011). Otherwise, they have the power to hinder participation for example by using their authority which in turn can be imposed by organisational structures in hospitals (Efraimsson et al., 2004; Sainio et al., 2001). Second, personnel can influence patient participation among dementia resident with an inviting or non-inviting attitude (Helgesen et al., 2010). Personnel's inappropriate behaviour should consequently be identified and corrected to enhance patient participation. Lastly, relational skills can be used by nurses to succeed participation (Tobiano et al., 2015) in which nurses prioritize spending time with the patient (Henderson, 2000).

Even though nurses can impact participation positively and negatively, they can also experience several barriers in their work to stimulate patients to participate in their care. Patients' attitudes, cognition and willingness have been identified as hindered opportunities for participation (Aasen, Kvangarsnes, & Heggen, 2012; Tobiano et al., 2015). Passivity of patients can hinder personnel in the context of participation (Aasen et al., 2012). Moreover, patient cognition, the mental capabilities of a patient, can determine the success of patient participation (Tobiano et al., 2015). In this view, it is interesting to study how nurses deal with a decline in cognitive function of dementia patients in the implementation of patient participation in practice. Within previous studies on medical wards, nurses were able to ensure that patients knew the consequences of their choices and patients' preferences were incorporated into action. Most persons with dementia, however, will become dependent on healthcare professionals due to the deterioration in behaviour and thinking (Helgesen et al., 2014). The researchers studied patient participation in a Norwegian dementia care unit and concluded that patient participation in everyday life ranged from a high level to no participation at all i.e. nurses fully controlling the residents and related decisions. However, empirical evidence is required to gain a better understanding of patient participation in the dementia setting as it ought to be a complex phenomenon (Helgesen et al., 2014; Tobiano et al., 2015).

2.4 Conceptualizing patient participation

Although the two main conceptualizations of patient participation by Tutton (2005) and Sahlsten et al. (2008), presented in section 2.2, take different approaches and use various terms, they have one crucial feature in common, namely an established dynamic relationship between a nurse and a patient that facilitates the active engagement of patients in their care. This feature furthermore aligns with a definition of patient participation given by Phillips et al. (2014) which focuses on the *"active involvement of the patient in planning, delivery, monitoring and evaluation of their own care"* (p.68). In this view, the patient is any individual receiving care services provided by a healthcare entity. Patient participation has also been studied in the context of general nursing practice in Swedish hospitals (Sahlsten et al., 2007). Their description of patient participation highlights the position of patients to have *"the opportunity to participate in their own care, adjusted to ability and the current situation"* (Sahlsten et al., 2007, p. 631-632). Based on the definitions of Phillips et al. (2014) and Sahlsten et al. (2007), the following definition will be followed when referring to patient participation in this study: *"the opportunity for patients to actively participate in planning, delivery, monitoring and evaluation of their own care, adjusted to ability and the current situation".*

Since there is no exhaustive theoretical framework on how, and which elements of patient participation can be implemented in dementia care by healthcare personnel, the conceptual models of Tutton (2005) and Sahlsten et al. (2008) will be synthesized in this research. In this way, their apprehension of participation of older people in hospital care can be applied and extended to the knowledge on participation of elderly with dementia in nursing homes. This synthesis fits the qualitative character of this research to validate the current elements of patient participation in practice (Sahlsten et al., 2008) and to further investigate the complex phenomenon of patient participation in dementia care units (Helgesen et al., 2014).

2.5 Attributes of patient participation

As mentioned in section 2.3, there is a need for older people to be actively involved in their own care (Lyttle & Ryan, 2010). Nevertheless, establishing patient participation in the care for elderly with dementia is often seen as a losing principle in daily care (Helgesen et al., 2014). Moreover, patient's level of cognitive function is considered as essential to patient participation (Garcia-Ptacek et al., 2019), meanwhile this might be challenging for elderly with dementia as they face cognitive impairment.

On the basis of the earlier mentioned synthesis of Sahlsten et al. (2008) and Tutton (2005), this section will distinguish the elements of patient participation that will be examined within the context of dementia in this study. These attributes are an active mutual engagement in physical and intellectual activities, understanding the patient, an established relationship between healthcare personnel and patient and balancing patients' dependency and autonomy. The researcher can consequently construct the theoretical framework for researching patient participation in a dementia setting.

2.5.1 Active mutual engagement in physical and intellectual activities

A defining attribute of patient participation is an "*Active mutual engagement in intellectual and/or physical activities*" (Sahlsten et al., 2008, p. 6). An active mutual engagement requires an involvement from both healthcare personnel and patients throughout all aspects of nursing care. Crucial in this process are invitation, encouragement and support. In order to achieve patient participation in intellectual or physical activities, patients' willingness is required (Tobiano et al., 2015). One method to facilitate patient participation on medical wards is to plan with patients. Planning can achieve patient-centred care which, nevertheless, needs to be aligned with patients' willingness.

Koskela et al. (2015) claim that engagement in meaningful activity can improve the well-being and health of older people in care homes. Still, the need for meaningful actively is an unmet need of dementia residents (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). The focus on activities, however, can increase patient's physical ability such as improved mobility and flexibility (Forster, Lambley, & Young, 2010). Meaningful activities can be subdivided into physical, cognitive, social and leisure activities (Koskela et al., 2015).

That it can be a challenge to stimulate and provide activities for elderly with dementia has been acknowledged in the study of Hancock et al. (2006), in which daytime activities are another unmet need of dementia residents. Therefore, additionally research can look into the application of this category and how this process is influenced by healthcare personnel. As such, healthcare personnel have an important role to activate and support the patients during all phases of the nursing process (Sahlsten et al., 2008). To facilitate an active participation of patients, nurses can motivate residents verbally (Tobiano et al., 2015). Nurses, however, might also face difficulties considering the stimulation of activities among residents, for instance they need to balance individuals' wishes and what can be managed within the group setting (Tutton, 2005).

2.5.2 Relationship between healthcare personnel and patient

Even though Tutton (2005) and Sahlsten et al. (2008) address different elements of patient participation, they and other scholars (Angel & Frederiksen, 2015; Tobiano et al., 2015) emphasise the basis for participation, namely an established relationship between healthcare personnel and the patient. Tutton (2005) highlights the dynamic aspect once more as a prerequisite for patients to make their own decisions. Relationships based on hierarchies do not facilitate patients' abilities, only participative relationships do.

The patient-nurse relationship is considered as a major foundation for patient participation by Angel & Frederiksen (2015). Patients feel acknowledged if they have a good relationship with their carers. An exchange of information is required for patients to be able to understand and transfer it into knowledge. Having information is described as particular important for elderly patients (Orsino, Cameron, Seidl, Mendelssohn, & Steward, 2003). However, elderly with dementia often experience a progressive, gradual decline in communication ability (De Vries, 2013). This challenges healthcare personnel to find a way to communicate, especially as communication is essential to establish relationship and to engage residents in positive social activities (De Vries, 2013). If residents cannot easily understand verbal communication, non-verbal communication by nurses can be used to facilitate this process, including facial expression and touch. Patients will only feel stimulated to participate if they feel heard and listened to, which indicates the need for a dialogue (De Vries, 2013; Eldh, Ekman, & Ehnfors, 2006).

The patient-nurse relationship is not a static relationship, but one that requires cooperation and time. This relationship can be strengthened over time (Goodwin & Happel, 2007) and is seen as a kind of collaboration. In order to establish this collaboration and to ensue participation, nurse need to recognize the patient as an equal partner (Nilsson, From, & Lindwall, 2019; Sahlsten et al., 2007). It is argued that dialogue and continuity are necessary to create a caring relationship. A safe, caring relationship facilitates patients to participate, especially older patients (Lindberg et al., 2013) as it increases the establishment of trust between patients and caregivers.

Moreover, certain beliefs and values can underpin this relationship such as respect, trust, empathy and negotiation (Tutton, 2005; Penney & Wellard, 2007; Sahlsten et al., 2008). Eldh, Ehnfors, & Ekman, (2004) concluded that non-participation was due to a lack of relationship and the patient's control. Noticeably, in the study of Tobiano et al. (2005) nurses were perceived as busy and struggled to attend and prioritise personal care (Lomborg & Kirkevold, 2008). The opportunity for patient participation was thereby hindered by staff, as they did not attempt to build a relationship with their patients (Sahlsten et al., 2008).

A caring relationship is especially of importance for older people to experience participation (Lindberg et al., 2013). Healthcare personnel can positively and negatively impact this relationship. On one hand, staff can be constrained by the organizational structures which in turn can stimulate them to use their authority. This can result in anxious patients (Angel & Frederiksen, 2015). Whereas on the other hand, by establishing an emotional connection with the patient, staff can interpret the wishes of this vulnerable patient group (Tutton, 2005). This has been addressed by another study, performed by Aadal and Kirkevold (2011), which shows that the patient's ability to participate can be reduced when limited in relation to emotion and attention. As such, a precondition for participation is an emotional and motivational conformity to the other's concerns (Angel & Frederiksen, 2015). Patient participation remains a challenge for nurses and awareness is necessary for its facilitation (Tutton, 2005).

As suggested by Sahlsten et al. (2008) empirical studies should elaborate on the meaningful, mutual interaction and relationship between practitioners and patients in order to optimize patient participation. That is why this research incorporates both attributes, interaction and relationship between the patient and practitioners, as elements discussed in interviews with healthcare personnel to further the knowledge on how it effects patient participation.

2.5.3 Understanding the patient

To strengthen the relationships between staff and patients, staff members need to understand and know the person in order to establish participation in daily care (Tutton, 2005; Sinclair et al., 2020). As argued by Tutton (2005) understanding a person can be divided into four categories: 1) personal history, 2) knowing the person, 3) connecting with the person, and 4) understanding disease. Some continuity of care has long been known for the significant support to understand and to know the patient (Jenny & Logan, 1992). The nurses' continued contact with the patient is an instrument to actively involve patients rather than solely treating them as 'older people' (Morse, Bottorff, Neander, & Solberg, 1991; Tutton, 2005).

Knowing a patient's biography and history facilitates the connection between patient and staff, the knowledge about the care they need and the opportunity for change (Tutton, 2005). Understanding the illness and dependency, the latter will be addressed in the next section, enables health care personnel to interact with the patients and to look for opportunities to let patients participate in their care (Tutton, 2005).

Another category that is of high importance in the care for dementia is the connection with the person, which allows staff to pick up cues and to identify appropriate actions (Tutton, 2005).

Difficulties in speech and language can challenge the communication for people with dementia (Banovic, Zunic, & Sinanovic, 2018). Picking up on cues such as emotional concerns or needs, can facilitate healthcare personnel to remain connected with the patient (McEvoy & Plant, 2014).

The last category, knowing the patient, has been defined as a crucial prerequisite for finding the best level of participation for dementia residents (Helgesen et al., 2014). Knowing the patient has been valued as a significance contribution of nursing to quality patient care (Jenny & Logan, 1992). Knowing the patient enables nurses to know patients' preferences, interests and feelings. In this way, staff can adjust the daily care to the life patients like to live (Tutton, 2005). In the light of this study it is important to research how nurses enhance knowing the patient, as it determines to which degree the level of participation of each individual has been ensured (Helgesen et al., 2014).

2.5.4 The degree of control healthcare professionals give over to the residents

In the light of the challenges faced by healthcare personnel in dementia care residents, the degree of nurses' control has been chosen as the last attribute. Older people seem vulnerable in the area of autonomy and nurses are more likely to take over their participation quickly (Efraimsson et al., 2004; Tutton, 2005). There is an ethical dilemma concerning patients' increased dependency and loss of autonomy (McLaughlin et al., 2010). This dilemma can be found both in home care (Smebye, Kirkevold, & Engedal, 2016) and residential care (Helgesen et al., 2014). To establish person-centred dementia care, the autonomy of dementia patients' needs to be respected and promoted (Edvardsson, Winblad, & Sandman, 2008). Autonomy and older people's dignity are often undermined in the provision of healthcare (Lothian & Philp, 2001). Autonomy can be defined as the "individual control of decision making and other activities" (Lothian & Philp, 2001, p. 668). Autonomy for elderly is an important aspect to ensure good quality of life (Edwards, Staniszewska, & Crichton, 2004).

Dementia may be a threat to a patient's dignity, as forcing residents' decisions could be regarded as normal since the residents are demented (Helgesen et al., 2014). Decision-making for dementia residents is as a complex phenomenon, in which three parties can be directly involved: residents, health care personnel (Helgesen et al., 2014; Sinclair et al., 2020) and family members (Petriwskyj et al., 2014). Personnel can make decision on behalf of the residents as well as stimulate residents to make their own decisions. As such, nurses can eliminate the power of patients but on the other hand, have the ability to empower patients in the decision-making by involving them as well.

The degree of patients' participation depends on nurses' level of control. Sahlsten et al. (2008) and other studies (Fitzmaurice et al., 2005; Longtin et al., 2010; Murray et al., 2001) show that patients can be educated to participate in their own care and organization of care, and that their participation can improve their disease control. Nurses are highly important in empowering and supporting patients to become participatory. As such, they have to surrender control to the patients which entails equality, responsibility and negotiation (e.g., Eldh et al., 2004; Tutton, 2005; Sahlsten et al., 2008). In this way, responsibility is given back to the patients which can be facilitated by providing options to choose from. Moreover, nurses can support patients to take their own responsibility by recognizing the patient as equal and having control (Sahlsten et al., 2008). There is, however, a tension between maintaining a sense of autonomy while accepting dependency on others at the same time between patients and staff (Tutton, 2005). Therefore, this balance is incorporated as an attribute of patient participation, as it is found in the theoretical ideal of patient participation but often neglected in reality in the care for dementia residents (Helgesen et al., 2014).

2.6 Theoretical framework

The current understanding of patient participation in healthcare mostly originates from evidence on medical wards (e.g., Sahlsten et al., 2007; Tutton, 2005; Tobiano et al., 2015), from insights of research on the benefits of patient participation (e.g., Lauri & Sainio, 1998; Phillips et al., 2014) or from an empirical study in specialized care units within one country (Helgesen et al., 2014). This thesis addresses the question of how patient participation can be implemented for dementia patients and more specifically how nurses can enable patients to become actively involved in their own care.

The starting point of this research is the experience of health care professionals regarding patient participation in caregiving for elderly with dementia. In order to study how health care professionals influence patient participation in the provision of dementia care within the selected case, the conceptualizations by Tutton (2005), Sahlsten et al. (2008) are primarily used. Further to these perspectives, additional insights of other authors are incorporated to study patient participation in practice. Furthermore, as discussed in section 2.2, explicit validation of the proposed attributes of patient participation, consequently, will be verified (Sahlsten et al., 2008).

No comparable research has been conducted on the applicability of these general nursing attributes of patient participation within dementia care. These attributes are not specified to the care for elderly with dementia, in which healthcare professionals deal with progressive impacts of residents' illnesses. Norwegian studies by Helgesen et al. (2010; 2014) have been conducted within a comparable dementia setting. Their emphasis was, however, not on the verification and applicability of general attributes of patient participation within their setting. As far as known today, no comparable study has been conducted in the Netherlands. Therefore, this study contributes to the expertise on the empowerment of dementia residents by building on the knowledge of patient participation within this specific context.

Chapter 3 -Methodology

In this chapter the methodological choices concerning the research will be made explicit. First of all, the type and design of research will be elaborated on. Secondly, the scope of the research will be presented, and attention will be given on where and how the qualitative data has been collected. Further explanation on the relevant concepts used during the interviews and data analysis follows. Relevant quality issues and research ethics will also be discussed.

3.1 Research strategy

The purpose of this study was to gain insights in the experiences of healthcare professionals in relation to participation of dementia residents in a nursing home to empower elderly, chronically ill patients in their health processes. The associated research question was formulated as: *"How do health care professionals influence patient participation in a specialized dementia care unit in a Dutch nursing home?".* A theory-driven research was conducted to answer the question. As little is known in the current literature on nurses' influence on patient participation among elderly with dementia, this research aimed to contribute to existing knowledge in two manners. First, this research attributes to knowledge on the elements of patient participation in the context for dementia residents in order to verify the attributes in practice. Secondly, this study aims to generate insights on the importance of healthcare professionals to implement patient participation in this specific context.

A qualitative research method seems to fit this thesis best, as it helps to explore details and foundations of interaction between nurses and dementia patients (Steihaug & Malterud, 2003). Qualitative research is aimed at the collection and interpretation of linguistic content in order to conduct a judgment on the (social) phenomenon in reality (Bleijenbergh, 2013). A qualitative approach was, therefore, the most relevant choice of method for this research in order to leave the participants' perspectives intact and to gain insights in their personal experiences within the dementia department.

This research follows both deductive and inductive reasoning. The initial research approach within this study was mainly deductive, which implies the application of existing theories to real-world observations (Ormston, Spencer, Barnard, & Snape, 2013). Regarding the concept of patient participation, present literature already acknowledged the lack of clarity regarding definition, elements and processes (Longtin et al., 2010; Phillips et al., 2014; Sahlsten et al., 2007). Nevertheless, Sahlsten et al. (2008) and Tutton (2005) both studied the role of patient participation in general nursing practice to get a cohesive understanding on how to involve patients in their own care. Hence, these theoretical frameworks served as the theoretical foundation of the current research. New empirical findings, however, are required to get a better understanding of the participation of demented elderly in more depth (Helgesen et al., 2014). Next to that, further insights in the role of nurses in terms of the relationship and communication between staff and patients are necessary to be investigated in practice. Therefore, an inductive approach enables the researcher to derive concepts, themes and models from raw data (Thomas, 2006). Within this thesis, the inductive approach facilitated the researcher to maintain an open attitude towards the data and to build on new ways of understanding within dementia care. The combination of a deductive and inductive approach supports the aim of this thesis, as such that theories on patient participation in hospital settings can be adopted and verified to dementia settings.

3.2 Research design

The research design of this study consists of a single case study, namely the department within a Dutch nursing home. A case study is an in-depth description and analysis of a phenomena within its real-life context (Merriam & Tisdell, 2015; Yin, 2014). Studying a case study allows to create theoretical constructs, propositions and/or midrange theory from the empirical evidence (Eisenhardt & Graebner, 2007). Because of the time and resources restrictions the scope of this study is one single case study.

Patient participation has primarily been studied on medical wards but not often in dementia care units in nursing homes (Helgesen et al., 2014). In this view, a case study fits this study design to be able to give an in-depth description of patient participation in its real-life context, namely the nursing home located in the Netherlands.

Regarding the current knowledge on patient participation, existing literature already indicated general attributes of patient participation in the context of caregiving which will serve as the framework of this thesis. As such, the four indicators and sub-dimensions as presented in section 2.5 will be used as a starting point for the interviews, to study and understand patient participation processes in care for dementia residents. Semi-structured, in-depth interviews were conducted to propagate nurses' views and the meanings they attribute to them. Semi-structured interviews are used to seek views on a focused topic (Hammarberg et al., 2016). In this research the focus was on what factors influence the participation of elderly residents with dementia. In-depth interviewing is a technique that can be conducted to explore respondents' perspectives on a particular program or idea (Boyce & Neale, 2006). In this research, this qualitative research technique is most appropriate to gain insights into the nurses' perspectives on the implementation of patient participation in this case study.

3.3 Case description

For this study, empirical research was conducted at one of the two small-scale housing units for dementia patients within the nursing home located in the Eastern part of the Netherlands. The nursing home is part of a healthcare organization that is a provider of both home care and residential care.

The organisation organises care around the opportunities and wishes of clients. Therefore, the focus is not solely on providing medical care but to ensure the well-being of clients likewise. In 2018, the location was entirely renovated to meet the new Dutch government guidelines for nursing homes. Since the renovation, the nursing home offers two different types of care, divided into 40 two-room apartments and 24 care studios. Firstly, clients can decide to live in "Living with Care" apartments. These apartments are equipped to provide somatic care for clients with physical impairments. Secondly, the nursing home offers rooms with a great deal of attention to dementia cases. This concept is called "Small-Scale Housing" or specialized dementia care units. The nursing home has two small-scale living areas, each area consists of twelve clients. Each living area has a common living room in which recognisability, homeliness and privacy are the most important principles. The care is specifically focused on supervision and nursing. The provision of care is client-focused, which requires a specific mindset from both clients and staff.

The studied department is one of the two small-scale living areas and provides continual care for elderly with dementia. The daily structure is based on a permanent team of health care professionals and volunteers. Among eighteen employees work at this specific department, such as nurses, caregivers individual healthcare, care assistants and healthcare hostess.

As this department finds it important to pay attention to activate their residents, it seemed to be a suitable and interesting department to study patient participation and to conduct this research. Moreover, after discussing the research proposal with both the location manager and the coordinating nurse, it appeared that the department was highly interested in this research. This department recently updated their annual plan in which patient participation is one important pillar. One point of improvement is the provision of individual activities. As the department expects a proactive approach from its employees towards patient participation, research can uncover the different work approaches within the team. Consequently, the department was open for conducting the research on the implementation of patient participation by their healthcare professionals.

3.4 Data collection

To gain an in-depth insight in the nurses' views and experiences on the participation of dementia residents, semi-structured questions were included in the interview guide. Interviews can facilitate rich descriptions of participants' experiences and the perspectives on a phenomenon (Baumbusch, 2010; DiCicco-Bloom & Crabtree, 2006). This fits the purpose of this study, to research the experiences of nurses within its real-life context. As the questions were semi-structured, the interview guide consists of open-ended questions (Ryan, Coughlan, & Cronin, 2009). This allowed the researcher for in-depth responses and an open approach to the data as such to elaborate on responses.

The interview questions were focussed on the current profession of the interviewee and the role of patient participation in the context of caregiving. All questions were based on their experiences. Interviewees were asked how they engage (or do not engage) in the implementation of participating the elderly residents with dementia in their specialized dementia care unit. The interview guide (Appendix A) was partly based on the conceptualization of both Tutton (2005) and Sahlsten et al. (2008), whereas also self-invented questions based on the exploratory meetings with the location manager and the coordinating nurse were added to the interview guide. This in order to meet the practical and scientific relevance of this study. For the interview guide, the concept patient participation had to be operationalised. In this study, four dimensions and related sub-dimensions of patient participation as described by Tutton (2005) and Sahlsten et al. (2008) were combined and used as the starting point to understand the processes of patient participation. Table 3-1 provides an overview of the operationalization of the concept 'patient participation' to translate the theoretical concepts to measurable interview indicators.

Dimensions	**Indicators**	**Interview items**
Relationship between nurse and patient [Tutton, 2005; Sahlsten et al., 2008]	Interaction (nurse-patient)	- Communication with dementia clients - Equal relationship - Meaningful dialogue [Sahlsten et al., 2008]
	Beliefs and values that underpin relationships [Tutton, 2005]	- Trust (between patients and staff and among staff themselves) - Respect (regardless of their condition or behaviour) - Negotiation (continuous dynamic process of communication, evaluation and change)
Active engagement in activities [Sahlsten et al., 2008]	Mutual engagement [Sahlsten et al., 2008; Tobiano et al., 2015]	- Initiative by nurse - Verbal motivation - Initiative by patient
	Meaningful activities [Koskela et al., 2015]	- Physical activities - Social activities - Leisure activities - Cognitive activities - Tools or guidelines - Willingness of clients
Understanding the patient [Tutton, 2005]	Understand illness/disease	- Access to information - Differences between functions - Education on dementia - Differentiation of living environments
	Personal history	- Access to medical history - Availability of information

	Knowing the patient	- Know what the clients like, their hobbies and preferences
	Connecting with the patient [McEvoy & Plant, 2014]	- Picking up cues
The degree of control healthcare professionals give over to the residents [Sahlsten et al., 2008]	Balance between dependency on others and maintaining a sense of autonomy [Tutton, 2005]	- Ethical dilemma to respect patients' autonomy and acknowledge patients' dependency at the same time
	Recognition of patient's responsibility [Eldh et al., 2004]	- Stimulate clients to take their responsibility - Taking over tasks - Degree of directness
	Degree of involvement [Helgesen et al., 2014; Sinclair et al., 2020; Petriwskyj et al., 2014]	- Decisions taken by health care personnel - Patients' involvement in decision-making - Family's involvement in decision-making

Table 3.1 Operationalization of patient participation

3.4.1 Sample selection

A purposive sample consisting of eleven participants was selected. A list of employees working at the department was provided by the location manager. Participants were selected based on differences in their function/level, years of experience and contract hours (FTE). During the explanatory meeting with the contact person, the need was stressed to include all profession to get an overview of how patient participation is enhanced within the team. Most often one caregiver individual healthcare, one care assistant and one healthcare hostess work together during the different shifts. Therefore, the inclusion criteria ensured that at least two employees of each profession were included. An overview of the different professions working at the department and the associated core responsibilities is presented in Appendix B. Participation was voluntary and all participants were given the option to accept or reject the invitation for an interview. There was also the opportunity to opt out at any time desirable.

During the explanatory meeting with the coordinating nurse, an email was sent to the care team to ask them whether they were willing to participate in the research. Afterwards, the contact person emailed all team members some practical information about the research and the interviews were planned. Since all participants are Dutch, the communication was in Dutch. This means that the information letter, the interview guide and the interviews were conducted and written in Dutch. The information letter and request form (Appendix C) described the project in more detail and permission was given by the participants in the form of a signature. Each interview took place in a face-to-face setting at the nursing home, a place they are familiar with. All interviews were audiotaped, with the informed consent of the participants, to stay as close to the data and to be able to transcribe verbatim immediately after completion. This allowed the researcher to fully concentrate on the conversation and only take little notes throughout the interview as well as not to miss important data.

Table 3-2 is added which lists the (pseudonyms of) respondents with relevant information for the research and the length of the interviews. Due to the Corona virus all interviews had to be conducted earlier than planned. In collaboration with the coordinating nurse and participants interviews were conducted two weeks ahead of schedule to conduct face-to-face interviews in the nursing home and to comply with the latest COVID-19 measures by the Dutch government.

Interviewees (fictious names)	**Function (EN)**	**Interview date**	**Interview duration**
Interviewee 1 - Peter	Care assistant (level2)	20-03-2020	1:10:00
Interviewee 2 - Ingrid	Caregiver individual healthcare (level3)	21-03-2020	1:03:25
Interviewee 3 - Adam	Nurse (level4)	23-03-2020	00:52:58
Interviewee 4 - Emma	Caregiver individual healthcare (level3) & specialized caregiver psychogeriatric	23-03-2020	1:20:00
Interviewee 5 - Lucas	Healthcare hostess	24-03-2020	00:59:35
Interviewee 6 - Benjamin	Care assistant (level2)	25-03-2020	00:50:00
Interviewee 7 - Susan	Care assistant (level2)	25-03-202	00:57:00
Interviewee 8 - Mark	Caregiver individual healthcare (level3)	25-03-2020	1:04:10
Interviewee 9 - Nienke	Healthcare hostess	26-03-2020	00:52:05
Interviewee 10 - Gerard	Nurse (level4)	28-03-2020	1:08:37
Interviewee 11 - Kim	Care assistant (level2)	13-04-2020	1:06:00

Table 3.2. Overview of interview participants

3.5 Data analysis

After the interviews had been conducted, the first step prior to the data analysis was to transcribe the interviews. The data had been transcribed and coded in Dutch. This according to the recommendations by Van Nes, Abma, Jonsson, & Deeg (2010) to stay in the original language as long as possible and to reduce misinterpretations which can occur due to language differences.

The process of coding has been performed with use of ATLAS.ti8. This computer-assisted qualitative data analysis software (CAQDAS) was found useful for the organization, exploration and coding of the retrieved data (Saunders, Lewis, & Thornhill, 2009). The first step of the data analysis was to carefully read all transcripts line by line. Conforming the initial research approach of this study, partly deductive, the theory served as the starting point of the data analysis. In this way, the current frameworks on patient participation can be validated and extended to the care for elderly with dementia. The four elements, or attributes, of patient participation (Tutton, 2005; Sahlsten et al., 2008) served as the main themes in the first round of coding. One way of validating research findings is to check the method, analysis and the interpretation of the researcher with the literature (Pyett, 2003). Therefore, the coding was an iterative process as the emerged codes were constantly compared to the main themes derived from the literature. However, relevant textual fragments that could not be categorized within the initial theoretical framework were coded with another category on the basis of actual terms used by the participants (data-grounded) or adopted terms that emerged from the data. In this way, the open approach towards the data was respected.

As subthemes were developed during the process of ordering and combining the initial codes, the initial coding tree was revised and refined. Subsequently, relationships among (sub)themes were indicated in order to identify facilitating and hindering factors to patient participation. The creation of a coding scheme increases the trustworthiness and validity of qualitative research (Hsieh & Shannon, 2005). Qualitative research requires not only further examination and comparing to academic literature, but also the involvement of research participants in the process (Torrance, 2012). As such, the working analytic framework was developed and is presented in a code tree (Appendix D) which was conducted on the basis of the code list (Appendix E).

3.6 Quality criteria

Throughout this study measures have been taken to ensure the quality of this qualitative study. Ensuring trustworthiness is essential when conducting quality research. The four criteria by Guba & Lincoln (1989) will be used to certify the concept of trustworthiness in this study: 1) credibility, 2) transferability, 3) dependability and 4) confirmability.

The first criterion, credibility, is concerned with the evaluation of the truth value or internal validity of the research (Hammarberg et al., 2016). This research aimed to ensure this through four means. First of all, theory triangulation assisted the researcher to validate and deepen the researchers' own understanding (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Multiple perspectives (e.g., Eldh et al., 2004; Tutton, 2005; Sahlsten et al., 2008) were used to establish the theoretical framework. Secondly, during the interviews the researcher restated the answers of the participants to determine accuracy. In this way, the participants were encouraged to explain their experiences in more detail. Thirdly, respondent validation was obtained by means of checking the initial data gathered, i.e. the transcripts of interviews, in order to check the correctness. This member check allowed participants to give feedback on their transcripts and to delete or add text to the original transcript or topic. To increase the anonymity of all participants pseudonyms were used where reference was made to quotations in this study. Lastly, peer-debriefing with the supervisor, mentor and fellow students assisted the researcher to reflect on her understanding and interpretation of the data.

Transferability, the second criterion, is often described as external validity or generalizability (Guba & Lincoln, 1989). It is concerned with the extent to which findings of this research can be applied, or translated, to other situations. As described by Guba & Lincoln (1989) one way to establish a certain degree of transferability is to provide a thick description of the case. In section 3.3 contextual information about this case study has been provided which facilitates readers to transfer this study to other (similar) cases.

The third criterion, dependability, is *"concerned with the stability of the data over time"* (Guba & Lincoln, 1989, p. 242). In the following ways the dependability of this research has been taken into account. Firstly, the processes within this study have been well-documented, as for instance the research strategy and analysis performed in this study. This enables readers to assess if research methodologies have been adequately followed and for future researchers to repeat the study (Shenton, 2004). Secondly, as member checks after completion of this research was not possible due to COVID-19, to protect the health of all stakeholders, other tools have been applied to test the methodological rigour. The systematic coding with the use of Atlas.ti impacts the reliability of this research positively. This coding software enabled the researcher to consequently assign codes to relevant text fragments. In addition, the initial framework, primarily based on literature, was used during the data analysis to concentrate on the aim of this research.

The last criterion that has been considered to certify the trustworthiness of this study is confirmability. This criterion refers to the degree to which data, interpretations, and outcomes of the research reflects the actual meanings of respondents and not the (biased) perspective of the researcher (Guba & Lincoln, 1989; Senton, 2004). In this research, the process of data collection, analysis and interpretation was elaborated on in the previous sections. Additionally, this research process is presented in Appendix D and E in which the analytic codes are displayed. The result chapter, moreover, referred to the interviews which increased the transparency and showed that the findings are shaped by participants.

3.7 Research ethics

While conducting research, it is important to be aware of the major ethical issues. The major ethical issues in research are: 1) beneficence, 2) informed consent, 3) respect for privacy, and 4) respect for anonymity and confidentiality (Fouka & Mantzorou, 2011). The nature of nursing can be incongruent with the ethics of conducting research. For instance, the professional code insists no revelation of confidential information of the patients.

The researcher needs to pay attention to each phase of the research in order to take ethical considerations properly into account and to be aware of the potential negative effects of the study

(Holt, 2012). This study, therefore, is designed in such a way to respect the dignity of all participants and to not do harm to any involved. Participants were informed on the aim and design of this study prior to the data collection. While conducting this research, nurses might face difficulties when it comes to confidentiality and anonymity. All informants, however, were verbally informed and had given written informed consent after the researcher provided sufficient information.

During the interviews, participants were asked for permission to record the interviews. Furthermore, all interviews took place in a private, quiet room within the nursing home to ensure the conversation was kept confidential. Additionally, all information obtained during the research was processed anonymously and was only issued for this research with the aim to contribute to existing literature from a nurse perspective. Respondents were given randomly assigned pseudonyms to make sure information cannot be traced back to the individual. A guarantee was given that participation could be halted at any time without any (work-related) consequences for them. During the entire process, the researcher remained in close contact with the coordinating nurse. The participants could contact the researcher via email or telephone at all times. All participants were asked whether they would like to receive the final research on paper, digitally or a short summary in their own language on paper. The results of this research will finally be presented during a team meeting consisting of the entire care team, location manager and researcher. Relevant results for the department will be provided and discussed. This meeting has been postponed due to circumstances and will take place when COVID-19 measures allows to.

This research is in accordance with the national Norwegian data protection and was approved by the Norwegian Centre for Research Data (NSD) (Appendix F).

Chapter 4 -Results

In this chapter an overview of the results will be presented. The code tree that emerged from the data analysis is presented in Appendix D. First, the facilitating and hindering factors of each theme will be discussed to provide an answer to the first supplementary question. Subsequently, the influence of healthcare personnel on patient participation will be discussed.

4.1 Facilitating and hindering factors to patient participation

The following section will present the data collected with relation to the first research question *"Which facilitating and hindering factors do health care professionals encounter in the implementation of attributes of patient participation?".* As indicated by the literature of Tutton (2005) and Sahlsten et al. (2008), attributes of patient participation can be divided in four main themes: 1) active mutual engagement in intellectual and/or physical activities, 2) understanding the patient, 3) relationship between nurse and patient, and 4) the degree of control healthcare professionals give over to the residents. The key facilitator and hinderances that have been derived from the interviews with the healthcare professionals will be presented in relation to the four attributes of patient participation.

4.1.1 Active mutual engagement in meaningful activities

From the stories of interviewees, it can be concluded that all the healthcare personnel are concerned with entertaining and keeping the residents active throughout the day. Emma emphasized this as: *"I see that all my colleagues are busy with the residents. You do not have to be busy with them all the time, it is alright to have some quiet time for a cup of tea. Furthermore, you can tell an attempt is made to keep the residents occupied".* Staff encountered several barriers to provide and stimulate residents. In light of the direction of this study, the most prevalent finding regarding the active mutual engagement in activities is the lack of guidance on physical stimulation as well as the required training in dementia to find opportunities for patient participation.

4.1.1.1 Providing and stimulating activities for elderly with dementia

Even though most employees are aware of the range of activities that can be undertaken, such as social, cognitive, physical and leisure activities not all participants actively stimulate the residents, in particular in physical activities.

On one hand, the physical activities that are scheduled in the team agenda and are read through at the beginning of the shift have been mentioned by all participants as a facilitator to physical activities. For instance, a couple of residents have to stay active with the use of an exercise bike which has been stated by some participants (Mark, Kim, Gerard, Susan, Benjamin, Adam, Emma) as a routine which they always undertake with the residents.

On the other hand, most participants described not being able to undertake spontaneous, unplanned, physical activities with the residents. Limited time (Ingrid, Benjamin), lack of tangible and human resources (Ingrid) and the negative influence of other residents (Gerard, Mark) were mentioned as barriers to engage residents physically. Some participants could not give an explicit explanation why they do not undertake physical activities: *"Hmm, that is a good question. No, I don't know why"* (Kim) and *"No, I actually don't know why"* (Adam). More specifically, various employees who are not specially trained in dementia care argued that they lack guidelines in terms of activities (Ingrid, Kim and Adam) and stimulation for dementia residents (Susan). Therefore, it can be argued that some professionals felt hindered by their lack of knowledge, expertise and awareness of how to activate the residents.

Furthermore, the data showed that the stimulation of cognitive activities is intertwined with initiating leisure activities (e.g. games). All participants mentioned the 'question game' which has been used to stimulate the cognitive function of residents as it triggers their memory. Lucas for instance explains that this game provides guidance to stimulate the elderly; *"Look at the past, that's the name of the game. It consists of many open-ended questions, not questions with an answer. I use that very often. I stimulate residents to think and answer for themselves".* The cupboard which is full of games facilitated some professionals (Gerard, Lucas, Benjamin, Emma) to choose a leisure activity. Additionally, talking with residents about COVID-19 or discussing the news(papers) is a form of cognitive stimulation (Peter, Emma, Gerard). In general, chitchatting with residents while drinking a cup of coffee or tea is experienced as a simple and convenient social activity for all professionals. The team leader illustrates this in the following quote: *"Just starting a conversation over a cup of coffee, that is obviously an activity as well.".*

4.1.1.2 Active mutual engagement

Mutual engagement in activities is closely linked to the provision and stimulation of activities by healthcare professionals within this research. This has been reflected by the initiatives of both residents and healthcare personnel. The negative attitude of residents towards every kind of activity has been perceived as an important barrier to participation. Nine out of eleven participants emphasized the passivity of residents, their lack of interest and their negative attitude towards activities. Throughout the interviews, Ingrid and Emma reflected on residents' willingness: *"Personally, stimulation is a tricky point because residents can be so condescending; they want nothing and rather just sit and do not do anything."* (Ingrid) and *"That initiative is not available in our group, no we have to come up with initiatives."* (Emma).

Employees in this case study seem to be aware of their responsibilities of residents' passivity. As such, professionals explained that they have to provide meaningful and interesting pursuits adapted to individual preferences (Emma) in a way that the residents feel useful (Mark, Lukas), for instance to peel potatoes (Peter, Ingrid, Adam, Emma, Lucas, Susan, Kim, Mark) and to set up the table (all participants). Once the so-called green light was given, residents were willing to participate. The latter has been illustrated by Gerard *"Most often I put the tablecloth on the table, and I observe what happens, mostly the residents take over. (…) The majority are willing to participate. But that happens because everyone helps and they stimulates each other, so to speak.".*

In conclusion, it appears that residents are dependent on the initiatives of healthcare personnel to be active, which sometimes is experienced as a burden on the personnel in addition to their job responsibilities. Additionally, the residents can influence each other both positively and negatively.

4.1.1.3 Balance between individual and group activities

All participants, except the specialized psychogeriatric caregiver (SPC), emphasized to balance activities within the group setting and one-on-one contact. Just over half of the respondents experienced this balance as a hindrance to stimulate activities among residents. This was partly due to the shortage of staff (Ingrid), individuals' preferences (Adam, Susan, Kim) and the attitude of the noisiest residents (Benjamin, Mark). More specifically, challenges for balancing group and patients' wishes can be found in employees blaming themselves for not doing enough. Mark expressed this feeling: *"There are twelve residents, and everyone is different and sometimes you really tried. (…) And then I wish someone were there. But maybe there is no point entertaining everyone".*

On the other hand, employees acknowledged that they do not always have to keep the group together. Sometimes there is a special demand for one-on-one contact between a patient and a healthcare professional. This has been facilitated by the available time especially during the weekend (Gerard) and the opportunity to have personal conversations in a patient's room (Peter, Gerard). Healthcare professionals experienced their responsibility to weigh up what is necessary at that specific time and who needs the attention more, rather than letting the residents' behaviour for instance restless and noise determine this as Nienke indicated: *"You have to alternate between the residents".*

4.1.2 Understanding the patient

Three components of 'understanding the patient' have been found. Throughout the interviews it became clear that the predefined categories 'personal history' and 'understanding disease' (Tutton, 2005) were closely linked because of the Electronic Health Record [EHR]. Therefore, findings will be presented jointly in the next section as available patient information. The most striking result to emerge from the data is the importance of dementia knowledge in order to understand the residents which was often hindered by the lack of dementia training, and the availability and access of resident's information.

4.1.2.1 Available patient information

Reading patients' bibliography, 'life history', 'medical data' and preferences and behaviour via the EHR, facilitated healthcare professionals to enhance patient participation. More specifically, the available information on patients' history facilitated personnel whether it be to provide background information in the case of a new arrival (Peter, Benjamin) or to represent habits, wishes and needs of residents (Susan, Gerard, Peter, Kim).

Furthermore, the EHR facilitated personnel to understand the disease and related behavioural problems likewise. Some participants (Nienke, Susan, Ingrid), however, mentioned that the absence of dementia training hindered them from finding opportunities to stimulate residents adjusted to the stage of their disease. Only a few professionals have had specialized training in dementia care (Gerard, Benjamin, Emma) on disease symptoms, behaviour and stimulation. Other ways that have been described as facilitators to understand patient's illness are using previous work experience in dementia care (Gerard, Emma) and learning from own personal network (Peter, Nienke).

However, the ability to understand information (Ingrid, Benjamin), the lack of detailed available information (Adam, Ingrid) and the limited access to information (Nienke) were experienced as barriers to understand the patient. The latter case especially applies to hostesses who do not have the same rights to information, due to privacy regulations, as other professions. In light of the focus of this study, participants mentioned hostesses as the most important stakeholders to stimulate residents in two manners. First, it is part of their job to involve and socially engage with the residents, for example during the cooking (Peter, Emma, Mark). Secondly, they have more time to spend on the group as they are not concerned with caring tasks and therefore experienced as extremely valuable by the team (Kim, Ingrid). Even though they have this responsibility, some colleagues referred to them as the least stimulating towards residents (Susan, Benjamin): *"The hostesses have less knowledge. We experience that a lot. In general, they are not so stimulating. They will do if being guided by us, but you just notice that they lack the knowledge."* (Benjamin). Regarding this matter, one hostess experienced consequences of the lack of access to information: "*They communicate changes on NEDAP (…) However, sometimes this lacks information as indicated in the EHR. (…) But like the disease, then I think it would be useful to know. As you then can maybe approach the residents differently."* (Nienke).

What can be concluded is that the access and availability of residents' information, via the EHR, facilitated healthcare professionals to understand and stimulate residents. On the contrary, not all professionals are educated on the different types and stages of dementia. This lack of knowledge has been encountered by professionals, especially hostesses, as a barrier to understand residents and to stimulate them in day-to-day life.

4.1.2.2 Connecting with the person

Data showed that picking up on signals and cues like residents' behaviour, facilitated healthcare personnel to remain connected with the patient. Healthcare personnel need to respond to signals in terms of residents' behaviour. One of the participants (Kim) mentioned a situation which illustrated healthcare personnel's responsibility to anticipate if residents are becoming fidgety or restless: *"For example, some residents are getting restless after lunch. That has not been documented in the EHR yet, but those things you will easily recognize. (…) By watching and observing, like who they are and what are their habits. You will notice that because you are concerned with the residents and you observe*". This highlights the importance of observation as a facilitator to understand the patient. In section 4.1.2.4. this will be discussed in more depth.

Throughout the interviews it became clear that the category 'knowing the patient' is highly interrelated with 'connecting with the person'. Moreover, healthcare professionals experienced knowing the patient as a facilitator to picking up signals (Emma, Gerard, Kim, Mark,). By knowing the patient, healthcare professionals can recognize residents' behaviour and are facilitated to pick up signals, for instance: *"We have a resident who starts to shout in the evening who is overstimulated. We have discussed this within our team with the specialized psychogeriatric nurse and that behaviour is just a signal that the resident is too tired."* (Mark). This example addresses the SPC as a facilitator, as a result from her completed training in dementia caregiving. Moreover, the SPC facilitates personnel to likewise know how to approach residents (Mark, Adam, Gerard, Kim, Peter, Susan). Participants did not experience specific barriers to connect with residents, nonetheless the following section will elaborate on generally experienced hindrances to understand residents.

4.1.2.3 Knowing the person

In the caregiving for elderly with dementia 'knowing the resident' is experienced as the most important factor. More specifically, knowing the patient is found to be a precondition to stimulate residents to participate. This phenomenon is often mentioned as two-sided, which means that the residents need to know the personnel and vice versa. Even though the residents have dementia, over 80% of the respondents experienced the significance of patients recognizing staff members. This if found to be highly essential in the establishment of a safe environment which facilitates personnel to get to know the person.

Furthermore, participants experienced several specific facilitators to get to know the person, for instance, the EHR provides information about the residents' preferences (Susan, Benjamin, Gerard, Mark, Adam), the hours on duty facilitate residents to get used to the personnel on duty (Mark, Susan, Benjamin) and observing the residents and their behaviour as a source of information by healthcare professionals (Peter, Mark, Benjamin). Observation is especially experienced as a general facilitator to understand patients and their needs at that moment: *"But if you observe the residents than you will recognize their behaviour. That is just really important"* (Peter). This facilitator has been emphasized by all participants, expect for Ingrid who expressed to have difficulties with the stimulation of residents. Participants used observation as a way to understand the patient and on the basis of that healthcare professionals are able to stimulate the level of participation for the individual resident by knowing individuals' characteristics.

Some participants experienced patients' behaviour as a hindrance to get to know the person, namely the so-called 'behavioural abnormalities'. More specifically, aggression among residents particularly was experienced as a hindrance to stimulate residents in their own care (Lucas, Adam, Ingrid, Kim). Professionals who mentioned patient's aggression but did not encounter this as a barrier, assigned this behaviour to the underlying reason, such as being ashamed (Susan, Mark, Peter), being dependent on healthcare personnel's guidance (Gerard, Benjamin) or denying the way dementia progresses (Susan, Benjamin). Knowing the person and recognizing their behaviour, as discussed in the previous section, involves basic knowledge on dementia care: *"If a resident becomes overstimulated, then you have to take someone separately or one-on-one contact also works. Thus, that is also some basic knowledge that is required.".* (Gerard). The lack of knowledge on dementia hindered healthcare personnel to get to know the person which is related to a certain mindset: *"Because I love the people as they are and I will always see the human behind the disease"* (Emma).

4.1.3 Relationship between nurse and patient

An established relationship between patient and practitioner is at the basis for patients to participate in their care (Tutton, 2005; Sahlsten et al., 2008). From the stories of interviewees, it can be concluded that all healthcare personnel agreed on the establishment of relationships with residents as key to stimulate the residents accordingly. This is displayed in the multiple facilitating factors experienced by the staff. The establishment of relationships was experienced as a natural consequence of taking care of dementia residents: *"It is not family I know that, but you will absolutely bond with the residents. Well, that just happens"* (Nienke). Nonetheless, how these relationships are strengthened and what facilitated or hindered the professionals differ and will be elaborated on in the following sections.

4.1.3.1 Interaction staff and patient

Communication was encountered as a facilitator to establish good relationships with residents: *"The communication. Indeed, know your client, that is just very important. I think that, consequently, you* *can establish a good relationship". (*Adam). Moreover, some professionals (Ingrid, Susan, Mark, Peter) were very careful in their communication that residents would feel listened to. Having a meaningful dialogue is still possible with dementia residents as participants experienced this in talks about religion and death (Mark, Adam, Susan, Peter) or COVID-19 (Ingrid, Gerard, Nienke, Peter, Emma). Irrespective of patients' ability to communicate and their dependency on their carers, within these dialogues the residents were seen as equal partners. In order to value residents as equal partners, healthcare professionals require a certain awareness and reflection as highlighted by Gerard: *"That is to be equal, standing next to each other on eyesight and not physically standing above someone. Residents experience literally how the other one stands, sits or lays down and yes then you aren't equal, and they would feel that likewise.".*

In a similar way, non-verbal communication facilitated the creation of a safe environment in which residents are stimulated to participate, for instance during the ADL (activities of daily living) (Peter). Non-verbal communication facilitated healthcare professionals to bond with residents by putting an arm around them (Ingrid, Gerard, Mark, Kim) or by eye contact (Mark, Gerard, Emma).

The progressive decline of residents' ability to communicate was, however, experienced by some participants as the only barrier to establish a relationship (Kim, Ingrid, Adam). Not knowing how to get through to the resident or how to assist verbally hindered professionals to understand and bond with the residents. Communication barriers were often linked to the advanced stage of dementia and related behavioural problems of residents (Kim, Mark). Interviewees did not encounter limited time nor workload as hindrances to establish relationships. Rather professionals prioritized bonding with residents, which was likely to occur in the little things throughout the day (Mark, Benjamin, Peter, Adam, Ingrid).

4.1.3.2 Beliefs and values

Besides the communication between dementia residents and healthcare personnel, different beliefs and values were experienced as a precondition to establish and strengthen relationships. The establishment of relationships between personnel and residents was facilitated by empathy (Emma, Kim, Mark), equality (Ingrid, Benjamin, Nienke, Gerard, Susan, Lucas), safety (Adam, Gerard, Emma, Mark, Ingrid), trust (Peter, Mark, Emma, Lucas, Susan, Benjamin, Gerard, Ingrid, Kim) and respect (Peter, Mark, Emma, Lucas, Susan, Benjamin, Nienke, Gerard, Ingrid, Kim). No significant data was found on the importance of negotiation, instead, collaboration was seen more essential as illustrated by Ingrid: "*We have to do it together during the day, I believe".*

Assumptions are made by the respondents that empathy is fundamental for patient participation. The data has shown that healthcare professionals show empathy in several ways, such as an understanding of the situation (Peter), having a warm feeling for the residents (Mark, Lucas), empathizing with residents (Nienke, Gerard), showing affectionate love for them (Emma, Mark, Kim) and feeling sorry for residents' declined ability (Nienke, Susan, Mark). Empathy facilitated personnel to bond with residents in a more personal way, as Susan illustrated this: *"It is important to give them attention, just personal attention. That you see the individual and not just the disease like Alzheimer, but that you value the person."*.

The data only showed that certain beliefs and values are required to establish relationships, the lack of which hinder bonding with the residents. For example, healthcare professionals need to value each individual resident, i.e. respect their dignity, through going along with residents' perception (Lucas, Emma, Gerard) or not arguing with residents (Peter, Benjamin, Emma): "*I won't argue with a resident because I know that in the case of dementia and aggression, if you would ramble on you can't form a bond, create trust and the resident won't feel safe enough. Then you would do more harm than good."* (Emma).

4.1.4 The degree of control healthcare professionals give over to the residents

Within theoretical assumptions of Eldh et al. (2005) and Sahlsten et al. (2008), nurses can become facilitators to patient participation by recognizing patients' responsibility and ability to have control. The data showed that the department aims to stimulate residents' autonomy by providing options for them to choose from, but encountered different facilitators and hindrances to accomplish this.

4.1.4.1 Recognition of the patients' responsibility

Over half of those questioned (Susan, Gerard, Benjamin, Kim, Peter, Emma), stimulated patients' responsibility by providing options to choose from in the daily care. This facilitated healthcare personnel to stimulate residents' independency on the one hand, whilst guiding residents to make decisions when they do not understand personnel's questions. In this study there was a coherence between the recognition of residents' responsibility and the guidance of residents to a certain degree. Adam, who is a nurse, reflected this as: "*Own responsibility, yes, I wonder to what extent the residents can take their own responsibility. I believe that we have to give direction yes. (..) I guess that happens automatically."*. This will be elaborated on in the section on the involvement of healthcare professionals in decision-making.

Various respondents expressed one factor that has been experienced as restricting participation: task-oriented nursing labour (Mark, Emma, Susan, Kim). A task-oriented view has been described as focused on rules, responsibilities and tasks, rather than 'going with the flow'. More specifically, task responsibility of those professionals in charge of medication can hinder the opportunity to stimulate residents' responsibility. As such, working with dementia residents requires a certain flexibility in which the healthcare professionals are dependent on patients' timing (Ingrid, Peter, Emma, Lucas). This has been summed up by two respondents as 'emotion-oriented care' (Lucas, Emma). Mark for instance explained that he found it difficult to let go of the rules, such as the scheduled time for medication, and to adapt to the situation. Whereas, Emma, practiced the same profession as Mark, addressed the need to think outside the box and to provide emotion-oriented care rather than to be task-oriented. This reasoning can be linked to the training in dementia care as well as the experience in dementia caregiving, as it touches on tailoring care to the needs of dementia residents.

4.1.4.2 Degree of involvement in decision-making

Three parties are involved within the decision-making: 1) residents, 2) healthcare personnel and 3) family members. The involvement of family in the decision-making was commented on by approximately four-fifth of the participants (82%). On one hand, this involvement facilitated personnel in the caregiving for residents as it was considered as a source of information. The engagement of family begins with residents' arrival (Peter, Ingrid, Adam, Emma, Nienke) in which habits, norms and values can be discussed. The documentation of these conversations, accessible via EHR, together with the treatment plan developed by other disciplines, were perceived as other facilitators to decision-making by all participants.

Still, it has been frequently noticed that the involvement of family within the decision-making can be contrary to residents' and/or personnel's' wishes. For example, the practicalities, such as medication and ADL-care, are primarily based on family's preferences. Patients' voices are often neglected during their arrival (Adam) as it is found easier to listen to relatives rather than residents as they sometimes are unable to express their wishes (Adam, Benjamin, Gerard, Ingrid). Participants explained that throughout the day, however, patients' preference will always be considered and listened to. Regardless of former expressed relatives' preferences, healthcare professionals involve residents in the daily care, in terms of clothing (Susan, Benjamin, Kim), washing (Gerard, Emma, Peter, Ingrid) and food (Lucas, Peter). This was illustrated by the following quote: *"Some people dislike taking a shower, because they didn't do that often in the past. Why is it then necessary now? (…) Although, in the morning it is up to me to decide. If the residents like to shower, that is not a problem for me, and we'll just take a shower".* (Ingrid).

The involvement of healthcare personnel in the decision-making can manifest itself in two ways. First, all participants experienced that residents need to be directed or guided in their behaviour. Due to their disease, residents might deal with overeating or undereating which requires vigilance and direction from the healthcare professionals. Verbal motivation (Gerard, Peter, Lucas, Benjamin, Susan, Mark) facilitated staff to raise residents' awareness and to involve them. Second, healthcare personnel can decide to take over certain tasks or responsibilities of residents only for *"what they cannot do, but that doesn't require a specific threshold right."* (Benjamin). This reflects residents' dependency on care. Some participants (Susan, Emma, Benjamin, Kim), however, experienced that professionals take over residents' involvement too quickly which hindered patient participation like *"especially the ones who already depend on us, then you maybe take over care entirely."* (Kim).

4.1.4.3 Balancing patients' autonomy and dependency

There is a continuous tension between accepting residents' dependency and maintaining their autonomy at the same time. *"Balancing on a thin tightrope"* (Emma) illustrates this tension which has been perceived as a challenge by participants in the day-to-day care. Stimulating residents' responsibility and autonomy has been the main point on the agenda during the last team meetings. Participants concluded that although they aim to achieve a shared vision, with regards to stimulating residents' autonomy, in practice this is hard to accomplish. Respondents emphasized the willingness of the team towards patient participation as a facilitating factor (Mark, Adam, Ingrid, Peter, Gerard). In reality, however, over 70% of the participants encountered differences between colleagues in the stimulation of patients' autonomy as a barrier (Kim, Nienke, Susan, Benjamin, Emma, Adam, Ingrid, Peter). Often colleagues take over the responsibility of the patient which is considered as an important barrier to stimulate residents, as described by Emma: *"Do we share the same vision? That is something that you should ask the team in capital letters."*.

The importance of respecting the autonomy for elderly has been acknowledged by all healthcare professionals. However, some respondents mentioned that they respect patients' choices at all times, whereas others persuade the residents by means of coercion. More specifically, employing compulsion is only found acceptable in the case of a medical reason or if the patient lacks understanding: *"If the resident is very incontinent , and it's really necessary in that moment and it can't be postponed; yes, than it is sometimes better to follow through and to be directive towards the resident."* (Gerard). Compulsion was, however, never used without reflection or team consultation as this way of working would always be discussed in team meetings (Kim, Mark, Gerard).

4.2 The influence of healthcare professionals on dementia participation

The results linked to the second research question *"How do healthcare professionals influence the implementation of patient participation"* will be presented in this last part of the result section. The attitude and behaviour of professionals became evident in the interviews and will firstly be discussed. Subsequently, certain features influencing professionals' opportunities will be presented as well as suggested tools that can be applied to overcome the experienced barriers as suggested by interviewees.

4.2.1 Attitude and behaviour of healthcare professionals

The role of nurses, as illustrated in section 2.3.1, is essential in the enhancement of patient participation. Data showed that healthcare professionals' attitude and behaviour can influence, positively and negatively, opportunities for patient participation significantly.

Over 60% of the interviewees often mentioned that patience and calmness are experienced as important traits a healthcare professional requires to stimulate patient participation (Nienke, Gerard, Lucas, Benjamin, Mark, Peter, Emma). More specifically, *"you have to be patient to stimulate it, because it just takes more time."* (Susan) and *"just stay calm and explain to them how they can do it."* (Benjamin) illustrated how it requires time and therefore patience to stimulate the residents. The required patience to deal with dementia residents is something that professionals develop over time and therefore it requires patience from the professionals themselves likewise. Learning over time is experienced as a facilitator to stimulate patients to participate by nine out of the eleven respondents.

The three participants (Kim, Adam, Ingrid) who experienced several barriers to participate patients in their own care, such as aggression among residents, residents' declining ability to communicate and the lack of activity guidelines, did not clarify specific behavioural traits nor attitudes healthcare professionals require to stimulate patient participation. The remaining participants, however, mentioned the implications of their behaviour and were aware of the opportunities to stimulate dementia residents.

Additionally, professionals who have worked with dementia residents for a longer time (Gerard, Emma) experienced the lack of self-reflection within the team as a barrier to patient participation. More specifically, self-reflection allows professionals to reflect on their behaviour, communication and attitude which in turn influences the understanding of residents as well as the establishment of a caring relationship: *"Find out why the residents react like that and how you can bend this reaction. Often this behaviour is due to your own attitude and behaviour."* (Gerard). This behavioural reflection and awareness are required as highlighted in the following: *"If we are busy, talk too much or just walk by residents then they will become restless and then they also don't know what to do.".* (Susan). These quotations reflect the importance of self-reflection on professionals' own behaviour and attitude as it influences dementia residents' behaviour and ability to participate.

As mentioned in section 4.1.4.1., task-oriented nursing labour hindered the opportunity for residents to participate. This is closely linked to the behaviour of healthcare professionals. As experienced by some participants (Ingrid, Kim, Emma, Lucas, Peter, Adam, Gerard), flexibility of both the work and healthcare professionals is required and facilitates the stimulation of dementia residents. This flexibility is highly relevant in the care for dementia patients as the provision of care depends on residents' needs and willingness. Therefore, a certain affinity with dementia residents is expected from healthcare professionals and in the absence of this has been experienced as a hindrance to stimulate the residents. This affinity is expected from everyone, including volunteers: *“We want to have a conversation first, to see if they have affinity with this specific target group.”* (Emma). Yet, this contrasts reality: *“Differences between individuals, yes, because one person is not the other one and some have more affinity or fun time than the others.”* (Lucas).

Lastly, to sense the residents, the so-called “*finger spitsen gefühl*” (Emma), facilitated healthcare professionals to let residents participate. Sensing the residents enables healthcare personnel to understand what the group needs (Emma), to understand what an individual needs such as physical contact (Gerard), to stimulate each individual resident (Mark, Lucas) and to respond to situations (Peter). Personnel with this certain touch or feeling stimulated other professionals within the team likewise. The SPC, in particular, facilitated staff to stimulate residents in terms of activities and on how to actively approach them. Sensing residents replaces the need for (consulting) guidelines in terms of how to stimulate the residents actively as illustrated by Mark: *“No, I have never consulted a manual. It is more what you observe, what you think and what you sense. That is the way in my opinion”.*

4.2.2 Mechanisms influencing healthcare professionals

Team, organizational and contextual features influenced the professionals from implementing patient participation. As described in section 4.1.4.3., more than half of the respondents expressed their concerns with regards to the shared vision within the team. Even though this vision, to stimulate patient participation, is well-known it is often not being applied in practice. However, there is no consensus on the underlying cause. The lack of knowledge (Susan, Adam, Benjamin), the unwillingness or ignorance of personnel (Emma), the insufficient feedback of colleagues (Peter, Gerard), passivity of colleagues (Gerard, Emma) or the amount of personnel (Ingrid) are all experienced by the participants. Team meetings are often addressed as possible moments to share information, build on team knowledge and strengthen the work culture, however the implementation could be more efficient. Especially, discussing residents and related behaviour abnormalities facilitated personnel in the past but currently does not happen (Adam, Ingrid, Gerard, Kim, Emma).

Besides team features, organizational features influenced healthcare personnel in the implementation of patient participation. First of all, professionals felt that the organizational structure, i.e. described as highly bureaucratical, hindered them in practice (Mark, Emma). A finding of note was the impact of architecture on opportunities to stimulate residents: *“I am really sorry for not being located downstairs. We do not even have a balcony where we would all fit in, that is such a missed opportunity. (…) I have discussed that so many times with the management. But, yes…”. (Mark).*

The same applies to the organizational culture which has been illustrated by Susan, "*I believe that we the organisation here is used to taking over too much care of residents, while they actually still can do much.*".

No significant correlation was found between perceived workload and patient participation within this study. However, some participants noticed that some colleagues experienced the pressure of their work. Those workers were worrying too much or being too task-oriented which impaired the flexibility of work. Therefore it can be argued that healthcare professionals' attitude and behaviour rather than contextual features limited personnel to participate residents.

4.2.3 Tools for healthcare professionals

Further analysis on the influence of healthcare professionals on patient participation showed that the experienced barriers can be overcome in several manners. Table 4.1 presents several tools which have been indicated by the participants as manners to stimulate patient participation especially within the current team. Tools in this view are manners, ways and instruments that can be implemented within the team to enhance patient participation.

As mentioned earlier, the SPC acts as a facilitator to understand residents. However, the proactive attitude and knowledge of the SPC is used too little in the team and can be taken more advantage of to stimulate patient participation: "*In that respect, we should make more use of our SPC. But well, that is still ongoing.*" (Adam) and *"The SPC looks further than I would do and we can use that as a starting point."* (Ingrid).

Tools for patient participation	*Social welfare employees*	*Specialized Psychogeriatric Nurse*	*Dementia training*	*Team training*	*Client evaluation in team meetings*
Susan		X	X		
Ingrid	X	X	X	X	X
Gerard	X	X		X	X
Benjamin	X		X		
Emma	X				X
Adam		X	X		X
Mark	X	X	X		
Lucas					
Kim	X	X	X	X	X
Peter					

Table 4.1 Overview of tools to overcome barriers of patient participation

Chapter 5 -Discussion and conclusion

The aim of this research was to provide empirical evidence on how healthcare professionals influence participation of elderly with dementia in specialized dementia care units. This was facilitated by eleven semi-structured interviews with healthcare professionals working in a Dutch nursing home. In this section a summary of the main findings will be presented, a reflection will be given on the research, followed by implications for theory and practice as well as recommendations for future studies. Conclusions drawn from this study will end this chapter.

5.1 Main findings

In the previous chapter, the supplementary questions were addressed as to gain more insights into which facilitators and hindrances to patient participation have been encountered by healthcare professionals and how they influence this process. Patient participation is investigated by means of previous research (Tutton, 2005; Sahlsten et al., 2008) on attributes determining patient participation.

As in line with theoretical assumptions by Koskela et al. (2015) this study confirms the division of meaningful activities into physical, cognitive, social and leisure activities. Healthcare professionals mostly experience difficulties in engaging the residents physically which supports previous findings on the physical ability of older people (Cohen-Mansfield et al., 2010; Iliffe et al., 2004). However, scheduled and planned physical activities can help to overcome this barrier. Residents' negative attitude challenges the opportunity to activate elderly, which confirms previous research (Aasen et al., 2012; Tobiano et al., 2015). This attitude can discourage other residents likewise, whereas mutuality between residents can influence participation positively and negatively. This result provides additional knowledge on the mutuality as identified by Sahlsten et al. (2007), which is likely to not only occur between nurse and patient.

This study supports previous research, which has emphasized the crucial role of nurses in the process of patient participation (Angel & Frederiksen, 2015; Helgesen et al., 2010; 2014; Tobiano et al., 2015). According to this research, healthcare professionals are required to reflect and to be aware of the implications of their behaviour and communication on dementia residents. The group of participants that experienced several hindrances to implement patient participation, is the group that did not mention specific required behavioural traits nor attitudes of healthcare professionals. This can be explained by nurses' need to reflect on their daily work as suggested by Tutton (2005). The current research provides contrapositive evidence of Tutton's (2005) theory, as personnel can negatively influence opportunities in care if they lack self-reflection. A remarkable result in this study was the task-oriented attitude which withheld nurses to provide emotion-oriented care. This confirms the theoretical assumptions of Sahlsten et al. (2008) and provides further evidence on the implications of emotion-oriented care for elderly with dementia as argued by De Lange (2004).

Besides self-reflection on health care professionals' behaviour (Tutton, 2005), they can influence opportunities for patients' participation positively by remaining calm and patient at all times and sensing the individual residents. This research shows that this seems particularly significant in the care for dementia residents, as residents can be aggressive, passive or limited in their communication and hence participants need to find opportunities. Nonetheless, observation facilitates personnel to understand the resident as well as picking up signals (McEvoy & Plant, 2014; Tutton, 2005), non-verbal communication (De Vries, 2013) and valuing residents as equal partners (Nilsson et al., 2019; Sahlsten et al., 2007).

Previous research has suggested that busy workloads could influence the success of patient participation (Tobiano et al., 2015) as they can struggle to prioritise personal care (Lomborg & Kirkevold, 2008). Although health care professionals in this study only addressed the consequence of busyness on the provision and stimulation of activities, it was not seen to influence the overall engagement of residents in their own care. This could be because of the view of healthcare professionals' that patient participation can be already facilitated in the "little" moments. Remarkably, a lack of available patient information together with the absence of specialized dementia knowledge led to a lack of tailored activities to the needs of residents. As such, this research provides additional insights of how specialized knowledge on dementia care is important to facilitate patient participation building on the knowledge of general nursing by Tutton (2005). In line with Lindberg et al. (2013) staff can be hindered by organizational features, such as the bureaucratical structures as found in this research.

Relationships between staff and patients were established on the basis of empathy, equality, safety, trust, respect and collaboration, which provides further evidence for values that underpin relationships (Penney & Wellard, 2007; Sahlsten et al., 2008). An interesting finding with regard to the focus of this research is that residents need to know and recognize their carers and vice versa. This reflects the essence of participative relationships which facilitates participation (Angel & Frederiksen, 2015; Tutton, 2005). No significant data was found on the importance of negotiation as suggested by Tutton (2005). This can be explained by participants' view on negotiation and collaboration. Hence, collaboration seems to be more applicable in the case of dementia care, as healthcare professionals feel obligated to work together with dementia resident, otherwise they will become irritable and agitated if their preferences are not being respected. This reflects professionals' acknowledgement of the importance to respect elderly's autonomy as suggested by Edwards et al. (2004).

As expected by literature of Tutton (2005) this research confirms the continuous tension between accepting residents' dependency and maintaining their autonomy at the same time. First of all, decision-making is influenced by three parties, namely residents, healthcare personnel and family members (Helgesen et al., 2014; Petriwskyj et al., 2014; Sinclair et al., 2020). In practice, professionals experienced the involvement of family members as challenging which is consist with Petriwskyj et al. (2014). On one hand, it facilitates personnel in decision-making to know residents' habits as described by family members. During the intake, however, residents' voices were often neglected, and family's wishes and preferences are considered more important than residents'. This research suggests that health care professionals are persistent to listen to and act on residents' preference throughout the day, which can be a result of collaboration as an underlying value. Additionally, healthcare personnel's involvement is often displayed in direction and guidance, adapted and dependent on residents' disease and behaviour (abnormalities). Sometimes staff takes over care too quickly, which hindered other professionals to participate the elderly. In this way, it can be argued that professionals hinder residents to participate, as they do not surrender enough control (Sahlsten et al., 2008). Even though professionals acknowledged patients' responsibility as in line with Eldh. et al (2004), responsibility is not fully given back to the residents by taking care over too quickly which is consistent with findings of Helgesen et al. (2014). Compulsion is only employed by personnel after consultations within the team and only if there is a medical necessity or lack of residents' understanding. These results contradict the claims of Helgesen et al. (2014) that nurses could use force without reflection.

5.2 Strengths and limitations

This study had a wide mixture of participants, as different professions, educational levels and experiences working at the department of the nursing home were included. This increases the richness of the data. It is important, however, to critically reflect on the various choices that have been made to conduct this research and to discuss a number of potential limitations that influence the results of this research.

Despite the mixture of participants, this research has been conducted in a turbulent period worldwide. At the time of conducting this research, especially during the data collection phase, COVID-19 was characterized as a pandemic. Consequently, the dependability of this research is impacted by the different ways of working, increased workload and working hours in the nursing homes. Nonetheless, throughout the interviews it became clear that addressing patient participation was even more essential in this turbulent period as residents were dependent on healthcare professionals because they were not allowed to leave the living area. Hence, this research raised awareness among the care team on how they could facilitate patient participation in other moments likewise.

Given the small sample size, caution must be exercised to the generalizability of the results. Due to the limited resources and the threat of COVID-19 only eleven interviews were conducted. Moreover, the credibility of this research could have been stronger if more triangulation would have taken place. Due to the circumstances, observations and member checks after completion were not possible due to Dutch health guidelines, lockdowns and moreover digital meetings would be too time consuming as nurses were needed in this turbulent time. To tackle those potential limitations, the researcher provided a detailed description of the case study and obtained data which enables other researcher to judge the transferability to other cases. The inclusion criteria seemed to provide a wide variety of perspectives which can facilitate transferability to other nursing homes, teams or departments. Furthermore, the systematic coding together with the (private) documentation of the research steps safeguarded the trustworthiness of this study to a greater extent.

Choices regarding literature in the establishment of the theoretical framework of this study should be reflected on additionally. This research has tried to synthesise the elements of patient participation by Sahlsten et al. (2008) and Tutton (2005) on the basis of care for dementia residents. Because of the (unmet) need of dementia residents, specific attributes were incorporated into the framework, such as the unmet need of meaningful activity for dementia residents (Cohen-Mansfield et al., 2015; Hancock et al., 2006) and the surrendering of control by nurses (Helgesen et al., 2014). Consequently, it must be considered that the synthesised attributes rather than the separate attributes such as emotional work and facilitation, may also influence the results found in this study. During the interviews, however, all elements of patient participation as constructed in the theoretical framework were discussed and all additional aspects mentioned by the participants were incorporated in the analysis. Therefore, all relevant aspects mentioned by the interviewees with regards to the subject of this research are expected to be taken into account.

Finally, it is important to reflect on the role of the researcher. The biggest challenge in this research was to delineate the research purpose. It was an iterative process and the researcher had to rely on her own understanding and interpretations. However, discussions with the supervisor, mentor and fellow students helped to structure researcher’s thoughts and to reflect the actual meaning of respondents. Additionally, ethical considerations as mentioned in section 3.7 were considered. Throughout the interviews, the concern was voiced by different participants on the anonymity of this research. From this, it can be deduced that ethics were highly important which can enhance the tendency to report socially desirable answers (Lavrakas, 2008). Nonetheless, this research cannot completely discount this social desirability even though the researcher tried to make participants more comfortable by encouraging them to share their own experiences.

5.3 Contributions and recommendations for future research

This study aims to contribute to existing literature in two manners. Firstly, the results of this research showed that various factors influence the implementation of patient participation in the dementia care setting. This study is building upon the knowledge of patient participation within general nursing practice (Tutton, 2005; Sahlsten et al., 2008). This study contributed to a broader understanding of how the attributes of patient participation are applicable in the context for dementia residents by means of identifying facilitating and hindering factors encountered by the healthcare professionals. Moreover, all the attributes identified in the theoretical framework of this study are verified in practice. It specifically highlights the importance of observation, non-verbal communication, valuing residents as equal and picking up signals to stimulate elderly with dementia. Through the application of these facilitators, professionals can enhance patient participation in specialized dementia care units.

Secondly, within this research the influence of healthcare professionals' attitude and behaviour are considered critical to create opportunities for elderly with dementia to participate. Professionals can influence patient participation negatively and positively. Professionals, however, need to be aware of their influence. This study highlights the theoretical hypothesis as suggested by Helgesen et al. (2014) and Tutton (2005) of the required discussion between healthcare professionals to raise their awareness of patient participation. This thesis contributes to knowledge of patient participation within dementia care as such that task-oriented care as a hindrance factor found within general nursing practice (Sahlsten et al., 2008) could be overcome by focussing on emotion-oriented care instead. This highlights the required flexibility of staff to tailor care to patients' timing and needs.

Besides the theoretical implications of emotion-oriented care, it suggests the urgency for policymakers to likewise take this into account. In this way, nursing labour within this case study and other residential care homes can be more tailored to the needs of dementia residents. This research is particularly helpful for specialized dementia care units that aim to strengthen existing capabilities of dementia residents by, for example scheduled physical activities as well as self-reflection of healthcare professionals. Moreover, this research addressed the required dialogue between professionals to raise their awareness which can help staff working in dementia departments to better understand how patient participation is, or can be, influenced within a unit. It is important for policy makers within nursing homes to focus more on training for healthcare professionals to understand the implications of their behaviour and attitude towards dementia residents. As such, a self-reflective environment can be created where discussions take place. As participants addressed during the interviews, discussions facilitated by questions such as *"How do you stimulate physical activities within your unit?"* and *"What is the role of patient participation within your team"* opened up new ways for them to critically reflect their (routine) decisions. This increases awareness among dementia caregivers to further increase opportunities for dementia residents' participation.

5.3.1 Recommendations for future research

Despite the fact that this research has several limitations, it can be the initiator of a line of future research concerning the influence of healthcare professionals and the necessary attitude to offer care that suits the requirements of patient participation in dementia care.

One avenue for further research on healthcare professionals' influence on patient participation is the combination of different research methods, to see whether the current findings are likewise reflected in comparable settings. As such, observations can verify and add insights into the non-verbal communication as well as the interaction between healthcare professionals and with their residents (Kawulich, 2005). Additionally, the time frame of the research must be extended, especially considering the turbulent time in which this research has been conducted. This extension would allow the researcher to interview participants repeatedly or to carry out observations for a longer time, since participation is seen as a dynamic process that changes over time (Tutton, 2005).

Another suggestion for future research is related to the choice of case study. This research has been conducted in a nursing home, more specifically a department, that is concerned with patient-centred healthcare as one of their pillars was 'patient participation'. Therefore, it would be interesting to study an organization, e.g. a nursing home, which is not particularly interested in enhancing patient participation to compare and conclude if that would change the conclusions drawn in this paper.

This research only considered the influence of healthcare professionals' attitude and behaviour on patient participation, but additional research can be carried out on the suggested tools healthcare professionals can apply to overcome the experienced barriers as briefly touched on in the result section.

5.4 Conclusion

Patient participation has long been acknowledged as a crucial component of high-quality care, but empirical evidence is needed in the care for elderly with dementia. In order to gain insights into the way patient participation is influenced by healthcare professionals, the research question of this study was defined as: *"How do healthcare professionals influence patient participation in a specialized dementia care unit in a Dutch nursing home?"*.

This research shows that the implementation of patient participation in specialized dementia care units is influenced by facilitating and hindering factors as well as healthcare professionals' attitude and behaviour. Personnel aim to stimulate residents' participation throughout the day by understanding residents, establishing relationships, balancing residents' dependency and independency, and providing and stimulating activities. Especially through picking up residents' signals such as behavioural abnormalities, non-verbal communication as a substitute for limited verbal communication, treating residents equally to bond with them and observing residents' behaviour to understand the patient. Nonetheless, healthcare professionals can be hindered in this process by residents' negative attitude, absence of knowledge on dementia care and the organizational structure. Most importantly, a precondition for healthcare professionals to enhance patient participation is self-reflection and awareness of the implications of their behaviour and attitude towards dementia patients. Besides their attitude and behaviour, healthcare professionals facilitate participation by providing emotion-oriented care which is highly important to accommodate dementia residents' fluctuating needs, preferences and timing as a result of their progressive cognitive impairment.

To conclude, patient participation is a complex phenomenon in dementia care which is directly influenced by healthcare professionals' attitude and behaviour. It is important for both dementia residents and healthcare professionals to feel stimulated and encouraged to enhance patient participation. To this end, a supportive environment can be established in which healthcare professionals have an awareness of the facilitating and hindering factors of patient participation and have the training and knowledge to empower elderly patients with dementia to participate in their care.

Chapter 6 -Bibliography

Aadal, L., & Kirkevold, M. (2011). Integrating situated learning theory and neuropsychological research to facilitate patient participation and learning in traumatic brain injury rehabilitation patients. *Brain Injury, 25*(7-8), 717-728.

Aasen, E., Kvangarsnes, M., & Heggen, K. (2012). Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. *Scandinavian Journal of Caring Sciences, 26*(1), 61-69.

Allen, D. (2000). "I'll tell you what suits me best if you don't mind me saying": "Lay participation" in health-care. *Nursing Inquiry, 7*(1), 182-190.

Alzheimer Nederland. (2020, January 6). *Mensen met dementie per gemeente.* Retrieved from Alzheimer-Nederland: https://www.alzheimer-nederland.nl/sites/default/files/directupload/factsheet-dementie-per-gemeente.pdf

Alzheimer Netherlands. (2019, May). *Factsheet cijfers en feiten over dementie*. Retrieved from Alzheimer-Nederland: www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie

Andrews, J., Manthorpe, J., & Watson, R. (2004). Involving older people in intermediate care. *Journal of advanced nursing, 46*(3), 303-310.

Angel, S., & Frederiksen, K. (2015). Challenges in achieving patient participation: a review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies, 52*(9), 1525-1538.

Banovic, S., Zunic, L., & Sinanovic, O. (2018). Communication difficulties as a result of dementia. *Materia socio-medica, 30*(3), 221-224.

Barkay, A., & Tabak, N. (2002). Elderly residents' participation and autonomy within a geriatric ward in a public institution. *International Journal of Nursing Practice, 8*(4), 198-209.

Baumbusch, J. (2010). Semi-structured interviewing in practice-close research. *Journal for specialists in pediatric nursing, 15*(3), 255-258.

Bleijenbergh, I. (2013). *Kwalitatief onderzoek in organisaties.* Den Haag: Boom Lemma.

Boyce, C., & Neale, P. (2006). *Conducting in-depth interviews: A guide for designing and conducting in-depth interviews for evaluation input*. Retrieved from Pathfinder International Tool Series: Monitoring and evaluating-2: https://www.measureevaluation.org/resources/training/capacity-building-resources/data-quality-portuguese/m_e_tool_series_indepth_interviews.pdf/view

Cahill, J. (1996). Patient participation: a concept analysis. *Journal of Advanced Nursing, 24*(1), 561-571.

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. (2014). The use of triangulation in qualitative research. *Oncology nursing forum, 41*(5).

Castro, E., van Regenmortel, T., Vanhaecht, K., Sermeus, W., & van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient education and counselling, 99*(12), 1923-1939.

Christofoletti, G., Oliani, M., Bucken-Gobbi, L., Gobbi, S., Beinotti, F., & Stella, F. (2011). Physical activity attenuates neuropsychiatric disturbances and caregiver burden in patients with dementia. *Clinics, 66*(4), 613-618.

Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M., Thein, K., & Regier, N. (2015). Which unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry Research, 228*(1), 59-64.

Cohen-Mansfield, J., Thein, K., Dakheel-Ali, M., & Marx, M. (2010). Engaging nursing home residents with dementia in activities: the effects of modeling, presentation order, time of day, and setting characteristics. *Aging & mental health, 14*(4), 471-480.

Cramm, J., & Nieboer, A. (2016). Is "disease management" the answer to our problems? No! Population health management and (disease) prevention require "management of well-being". *BMC Health Services Research, 16*, 500.

De Lange, J. (2004). *Omgaan met dementie. Het effect van geinte- greerde belevingsgerichte zorg op adaptatie en coping van men- sen met dementie in verpleeghuizen: een kwalitatief onderzoek binnen een gerandomiseerd experiment.* Rotterdam: Erasmus Universiteit Rotterdam: Academisch proefschrift.

De Vries, K. (2013). Communicating with older people in dementia. *Nursing Older People, 25*(4), 30-37.

Delaney, L. J. (2018). Patient-centred care as an approach to improving health care in Australia. *Collegian, 25*(1), 119-123.

DiCicco-Bloom, B., & Crabtree, B. (2006). The qualitative research interview. *Medical education, 40*, 314-321.

Edvardsson, D., Winblad, B., & Sandman, P. (2008). Person-centred care of people with severe Alzheimer’s disease: current status and ways forward. *The Lancet Neurology, 7*, 362-367.

Edwards, C., Staniszewska, S., & Crichton, N. (2004). Investigation of the ways in which patients’ reports of their satisfaction with healthcare are constructed. *Sociology of health & illness, 26*(2), 159-183.

Efraimsson, E., Sandman, P., Hydén, L., & Rasmussen, B. H. (2004). Discharge planning: ‘fooling ourselves?’– patient participation in conferences. *Journal of Clinical Nursing, 13*(5), 562-570.

Eisenhardt, K., & Graebner, M. (2007). Theory building from cases: Opportunities and challenges. *Academy of management journal, 50*(1), 25-32.

Ekman, I., Wolf, A., Olsson, L., Taft, C., Dudas, K., Schaufelberger, M., & Swedberg, K. (2012). Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *European heart journal, 33*(9), 1112-1119.

Eldh, A. (2019). Facilitating patient participation by embracing patients' preferences—A discussion. *Journal of Evaluation in Clinical Practice, 25*(6), 1070-1073.

Eldh, A. C., Ekman, I., & Ehnfors, M. (2006). Conditions for patient participation and non-participation in health care. *Nursing ethics, 13*(5), 503-514.

Eldh, A., Ehnfors, M., & Ekman, I. (2004). The phenomena of participation and non-participation in healthcare experiences of patients attending a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing, 13*(5), 239-246.

Ferreira, A. R., Martins, S., Dias, C. C., & Fernandes, L. (2016). Dementia severity among institutionalized elderly: Are there more unmet needs? *European Psychiatry, 33*(1), 187-188.

Fitzmaurice, D. A., Murray, E. T., McCahon, D., Holder, R., Raftery, J., Hussain, S., . . . Hobbs, F. (2005). Self management of oral anticoagulation: randomised trial. *BMJ (Clinical research ed.), 331*(7524), 1057.

Forster, A., Lambley, R., & Young, J. (2010). Is physical rehabilitation for older people in long-term care effective? Findings from a systematic review. *Age Ageing, 359*, 169-175.

Fouka, G., & Mantzorou, M. (2011). What are the major ethical issues in conducting research? Is there a conflict between the research ethics and the nature of nursing? *Health Science Journal, 5*(1), 3-14.

Garcia-Ptacek, S., Dahlrup, B., Edlund, A., Wijk, H., & Eriksdotter, M. (2019). The caregiver phenomenon and caregiver participation in dementia. *Scandinavian Journal of Caregiver Participation, 33*(2), 255-265.

Goodwin, V. A., & Happell, B. (2007). Psychiatric nurses' attitudes toward consumer and carer participation in care: Part 1- exploring the issues. *Policy, Politics, & Nursing Practice, 8*(4), 276-284.

Gopee, N., & Galloway, J. (2017). *Leadership and management in healthcare.* London: Sage.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation.* Newbury Park, CA: Sage.

Guldager, R., Willis, K., Larsen, K., & Poulsen, I. (2019). Nurses’ contribution to relatives’ involvement in neurorehabilitation: Facilitators and barriers. *Nursing open, 6*(4), 1314-1322.

Halskov, G., Lauridsen, S., & Hoffman, P. (2017). Patient involvement in home health care: Elderly patients' perspectives on roles and responsibilities in the collaboration with home care nurses. *International Journal of Integrated Care, 16*(6), 1-8.

Hammarberg, K., Kirkman, M., & De Lacey, S. (2016). Qualitative research methods: when to use them and how to judge them. *Human Reproduction, 31*(3), 498-501.

Hancock, G., Woods, B., Challis, D., & Orrell, M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry: A journal of psychiatry of late life and allied sciences, 21*(1), 43-49.

Hansson, E., Ekman, I., Swedberg, K., Wolf, A., Dudas, K., Ehlers, L., & Olsson, L. (2016). Person-centred care for patients with chronic heart failure - a cost-utility analysis. *European heart journal, 15*(4), 276-284.

Heeringa, J., Mutti, A., Furukawa, M., Lechner, A., Maurer, K., & Rich, E. (2020). Horizontal and vertical integration of health care providers: a framework for understanding various provider organizational structures. *International Journal of Integrated Care, 20*(1), 2.

Helgesen, A., Larsson, M., & Athlin, E. (2010). 'Patient participation' in everyday activities in special care units for persons with dementia in Norwegian nursing homes. *International journal of older people nursing, 5*(2), 169-178.

Helgesen, A., Larsson, M., & Athlin, E. (2014). Patient participation in special care units for persons with dementia: A losing principle? *Nursing Ethics, 21*(1), 108-118.

Henderson, S. (2000). Patient participation determined by nurses' attitudes toward caring. *International Journal for Human Caring, 4*(1), 30-35.

Hilderink, H., & Verschuuren, M. (2018). *Volksgezondheid Toekomst Verkenning 2018: Een goed vooruitzicht. Synthese.* Retrieved from Nederlands: Rijkinstituut voor Volksgezondheid en Milieu: https://www.rivm.nl/bibliotheek/rapporten/2018-0030.html

Holmqvist, K. L., & James, I. (2019). Patient participation in municipal elderly care from the perspective of nurses and occupational therapists. *Nursing open, 6*(1), 1171-1179.

Holt, R. (2012). Ethical research practice. In G. &. Symon, *Qualitative organizational research* (pp. 90-108). Londen, England: Sage.

Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative health research, 15*(9), 1277-1288.

Hugo, J., & Ganguli, M. (2014). Dementia and cognitive impairment: epidemiology, diagnosis, and treatment. *Clinics in geriatric medicine, 30*(3), 421-442.

Iliffe, S., Lenihan, P., Orrell, M., Walters, K., Drennan, V., Tai, S., & SPICE Research Team. (2004). The development of a short instrument to identify common unmet needs in older people in general practice. *British Journal of General Practice, 54*(509), 914-918.

Institute of Medicine. (2001). *Crossing the quality chasm: a new health system for the 21st century.* Washington DC: National Academies Press.

Jenny, J., & Logan, J. (1992). Knowing the patient: one aspect of clinical knowledge. *Image: the jrounal of nursing scholarship, 24*, 254-258.

Kawulich, B. (2005). Participant observation as a data collection method. *Forum qualitative Sozialforschung / Forum: qualitative social research, 6*(2).

Kettunen, T., Poskiparta, M., & Karhila, P. (2003). Speech practices that facilitate patient participation in health counselling - A way to empowerment. *Health Education Journal, 62*(4), 326-340.

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advance Nursing, 69*(1), 4-16.

Kolovos, P., Kaitelidou, D., Lemonidou, C., Sachlas, A., & Sourtzi, P. (2016). Patients' perceptions and preferences of participation in nursing care. *Journal of Research in Nursing, 21*(4), 290-303.

Koskela, S., Jones, F., Clarke, N., Anderson, L., Kennedy, B., Grant, R., . . . Hurley, M. (2015). Active Residents in Care Homes (ARCH): study protocol to investigate the implementation and outcomes of a whole-systems activity programme in resident care homes for older people. *Physiotherapy, 103*(1).

Kuipers, S., Cramm, J., & Nieboer, A. (2019). The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. *BMC health services research, 19*(1), 13.

Lauri, S., & Sainio, C. (1998). Developing the nursing care of breast cancer patients: an action research approach. *Journal of Clinical Nursing, 7*(5), 424-432.

Lavrakas, P. (2008). *Encyclopaedia of survey research methods* (Vols. 1-0 ed.). Thousand Oaks, CA: Sage Publications.

Levesque, J., Harris, M., & Russell, G. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health, 12*(1), 18.

Lillekroken, D., Hauge, S., & Slettebø, Å. (2015). Enabling resources in people with dementia: a qualitative study about nurses´ strategies that may support a sense of coherence in people with dementia. *Journal of Clinical Nursing, 24*(21-22), 3129-3137.

Lindberg, E., Persson, E., Hörberg, U., & Ekebergh, M. (2013). Older patients' participation in team meetings- A phenomenological study from the nurses' perspective. *International Journal of Qualitative Studies on Health and Well-being, 8*, 21908.

Lomborg, K., & Kirkevold, M. (2008). Achieving therapeutic clarity in assisted personal body care: professional challenges in interactions with severely ill COPD patients. *Journal of Clinical Nursing, 17*(16), 2155-2163. Retrieved 3 3, 2020, from https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2702.2006.01710.x

Longtin, Y., Sax, H., Leape, L., Sheridan, S., Donaldson, L., & Pittet, D. (2010). Patient participation: current knowledge and applicability to patient safety. *Mayo Clinic proceedings, 85*(1), 53-62.

Lothian, K., & Philp, I. (2001). Maintaining the dignity and autonomy of older people in the healthcare setting. *BMJ (Clinical research ed.), 322*(7287), 668-670.

Lyttle, D., & Ryan, A. (2010). Factors influencing older patients' participation in care: a review of literature. *International Journal of Older People Nursing, 5*(4), 274-282.

McEvoy, P., & Plant, R. (2014). Dementia care: using empathic curiosity to establish the common ground that is necessary for meaningful communication. *Journal of psychiatric and mental health nursing, 21*(6), 477-482.

McLaughlin, T., Feldman, H., Fillit, H., Sano, M., Schmitt, F., Aisen, P., . . . Stern, Y. (2010). Dependence as a unifying construct in defining Alzheimer's disease severity. *Alzheimer's & Dementia, 6*(6), 482-493.

Merriam, S., & Tisdell, E. (2015). *Qualitative research: A guide to design and implementation.* San Francisco, CA: John Wiley & Sons.

Morse, J., Bottorff, J., Neander, W., & Solberg, S. (1991). Comparative analysis of conceptualizations and theories of caring. *Image: The Journal of Nursing Scholarship, 23*(2), 119-126.

Murray, E., Davis, H., Tai, S. S., Coulter, A., Gray, A., & Haines, A. (2001). Randomised controlled trial of an interactive multimedia decision aid on benign prostatic hypertrophy in primary care. *BMJ, 323*(7311), 493-496.

National Clinical Guideline Centre (UK). (2012). Enabling patients to actively participate in their care. In *Patient Experience in Adult NHS Services: Improving the Experience of Care for People Using Adult NHS Services.* London, UK: Royal College of Physicians.

National Institute on Aging. (2017, December 31). *What Is Dementia? Symptoms, Types, and Diagnosis*. Retrieved from https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis

Nilsson, M., From, I., & Lindwall, L. (2019). The significance of patient participation in nursing care - a concept analysis. *Scandinavian Journal of Caring Sciences, 33*(1), 244-251.

Ormston, R., Spencer, L., Barnard, M., & Snape, D. (2013). The foundations of qualitative research. In J. Ritchie, J. Lewis, C. M. Nicholls, R. Ormston, & (Eds.), *Qualitative research practice: A guide for social science students and researchers* (2nd ed., pp. 1-23). London: Sage.

Orsino, A., Cameron, J., Seidl, M., Mendelssohn, D., & Steward. (2003). Medical decision-making and information needs in end-stage renal disease patients. *General Hospital Psychiatry, 25*(5), 324-331.

Penney, W., & Wellard, S. (2007). Hearing what older consumers say about participation in their care. *International Journal of Nursing Practice, 13*(1), 61-68.

Petriwskyj, A., Gibson, A., Parker, D., Blanks, S., Andrews, S., & Robinson, A. (2014). A qualitative metasynthesis: family involvement in decision making for people with dementia in residential aged care. *International journal of evidence-based healthcare, 12*(2), 87-104.

Phillips, N., Street, M., & Haesler, E. (2014). Measuring patient participation in healthcare: a comprehensive systematic review protocol. *JBI Database of Systematic Reviews and Implementation Reports, 12*(3), 68-88.

Pyett, P. (2003). Validation of qualitative research in the “real world”. *Qualitative health research, 13*(8), 1170-1179.

Rijksinstituut voor Volksgezondheid en Milieu. (2018). *De vergrijzing heeft grote impact of de volksgezondheid en zorg*. Retrieved from VTV-2018: www.vtv2018.nl/impact-van-de-vergrijzing

Ryan, F., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research: the one-to-one interview. *International journal of therapy and rehabilitation, 16*(6), 309-314.

Saei, A., & Rahimi, A. (2017). Collaboration of patients with mobility disabilities in caring: conceptual analysis. *Health in Emergencies and Disasters, 2*(4), 187-200.

Sahlsten, M., Larsson, I., Sjöström, B., & Plos, K. (2008, January). An analysis of the concept of patient participation. *Nursing home, 43*(1), pp. 2-11.

Sahlsten, M., Larsson, I., Sjöström, B., & Plos, K. (2009). Nurse strategies for optimising patient participation in nursing. *Scandinavian journal of caring sciences, 23*(3), 490-497.

Sahlsten, M., Larsson, I., Sjöström, B., Lindencrona, C., & Plos, K. (2007). Patient participation in nursing care: towards a concept clarification from a nurse perspective. *Journal of Clinical Nursing, 16*(4), 630-637.

Sainio, C., & Lauri, S. (2003). Cancer patients' decision-making regarding treatment and nursing care. *Journal of Advanced Nursing, 41*(3), 250-60.

Sainio, C., Lauri, S., & Eriksson, E. (2001). Cancer patients’ views and experiences of participation in care and decision making. *Nursing ethics, 8*(2), 97-113.

Saunders, M., Lewis, P., & Thornhill, A. (2009). *Research methods for business students* (5 ed.). Harlow: Pearson Education.

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information, 22*(2), 63-75.

Sinclair, S., Kondejewski, J., Schulte, F., Letourneau, N., Kuhn, S., Raffin-Bouchal, S., & Strother, D. (2020). Compassion in pediatric healthcare: a scoping review. *Journal of pediatric nursing, 51*, 57-66.

Smebye, K., Kirkevold, M., & Engedal, K. (2016). Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study. *BMC health services research, 16*, 21.

Soleimani, M., Rafii, F., & Seyedfatemi, N. (2010). Participation of patients with chronic illness in nursing care: an Iranian perspective. *Nursing & Health Sciences, 12*(3), 345-351.

Steihaug, S., & Malterud, K. (2003). Part process analysis: A qualitative method for studying provider-patient interaction. *Scandinavian Journal of Public Health, 31*(2), 107-112.

Tempfer, C., & Nowak, P. (2011). Consumer participation and organizational development in health care: a systematic review. *Wiener klinsche Wochenschrift, 123*, 408-414.

Thomas, D. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation, 27*(2), 237-246.

Timonen, L., & Sihvonen, M. (2000). Patient participation in bedside reporting on surgical wards. *Journal of Clinical Nursing, 9*(4), 542-548.

Tobiano, G., Bucknall, T., Marshall, A., Guinane, J., & Chaboyer, W. (2015). Nurses' views of patient participation in nursing care. *Journal of Advanced Nursing, 71*(12), 2741-2752.

Torrance, H. (2012). Triangulation, respondent validation, and democratic participation in mixed methods research. *Journal of mixed methods research, 6*(2), 111-123.

Tutton, E. M. (2005). Patient participation on a ward for frail older people. *Journal of Advanced Nursing, 50*(1), 143-152.

Vahdat, S., Hamzehgardeshi, L., Hessam, S., & Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making: a review. *Iranian Red Crescent medical journal, 16*(1), e12454.

Van Belle, E., Zwakhalen, S. M., Caris, J., Van Hecke, A., Huisman-de Waal, G., & Heinen, M. (2018). Tailoring of the tell-us card communication tool for nurses to increase patient participation using intervention mapping. *Journal of clinical nursing, 27*(3-4), 621-630.

Van Bussel, E. F. (2017). Dementia incidence trend over 1992-2014 in the Netherlands: Analysis of primary care data. *PLoS medicine, 14*(3), e1002235.

Van Nes, F., Abma, T., Jonsson, H., & Deeg, D. (2010). Language differences in qualitative research: is meaning lost in translation? *European journal of ageing, 7*(4), 313-316.

Williams, G., Freedman, Z., & Deci, E. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care, 21*(10), 1644-1651.

World Health Organization. (1978). *Primary health care: report of the International Conference on primary health care.* Geneva: World Health Organization. Retrieved from https://apps.who.int/iris/handle/10655/39228

World Health Organization. (2013). *Global action plan for the prevention and control of noncommunicable diseases 2013-2020.* Geneva: World Health Organization. Retrieved from World Health Organization: https://www.who.int/nmh/publications/ncd-action-plan/en/

World Health Organization. (2015). *World report on ageing and health.* Geneva: World Health Organization.

World Health Organization. (2017). *Global action plan on the public health response to dementia, 2017-2025.* Geneva: World Health Organization. Retrieved from https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

World Health Organization. (2019, September 19). *Dementia*. Retrieved from World Health Organization: https://www.who.int/news-room/fact-sheets/detail/dementia

Yin, R. (2014). *Case study research design and methods* (5 ed.). Thousand Oaks, CA: Sage.

Chapter 7 -Appendix

7.1 Appendix A: Interview guide

Interview guide for healthcare personnel of the Dutch nursing home (Dutch version)

Introductie

Goedemiddag, ik ben Jolande Radstaak, master student Europese Gezondheidszorg Management en Economie. Deze opleiding heb ik deels gevolgd aan de Erasmus Universiteit in Rotterdam en mijn specialisatie naar het management van de gezondheidszorg is gekoppeld aan de Universiteit van Oslo en het Management Center in Innsbruck. Op dit moment ben ik bezig met het afronden van mijn master, waarvoor ik een onderzoek moet uitvoeren. Met het onderzoek wil ik de strategieën en manieren van werknemers in de zorg omtrent patiënt participatie in kaart brengen. Het onderzoek zal worden uitgevoerd binnen de organisatie x met daarbij een focus op de afdeling x. Patiënt participatie en de manieren waarop deze gestimuleerd kan worden zal worden onderzocht aan de hand van dit interview en interviews met een aantal andere medewerkers van team E.
Patiënt participatie is nogal een vaag begrip in de literatuur, maar men kan het beschrijven als de actieve deelname van patiënten (en cliënten) in de zorg. Patiënten en cliënten hebben namelijk unieke ervaringen en kennis die kunnen bijdragen aan betere zorg voor hen en voor anderen. Het doel is om zorg beter te laten aansluiten bij de behoeftes en wensen van wat de cliënten nodig hebben.

Met jouw toestemming maak ik graag een audio-opname van dit interview, zodat ik het later kan uitwerken. Het interview zal anoniem worden verwerkt en jouw naam zal niet worden gepubliceerd. Mag ik de geanonimiseerde date gebruiken voor mijn onderzoek?
Uiteraard is alles wat gezegd wordt tijdens het interview vertrouwelijk en zijn alleen ik en mijn begeleider vanuit de Universiteit van Oslo op de hoogte van de inhoud van het gesprek. Uw leidinggevende, collega's en/of manager krijgen geen inzicht in uw persoonlijke antwoorden. Hierbij wil ik benadrukken dat elk antwoord goed is en er geen foute antwoorden gegeven kunnen worden. Ik moedig je aan om echt na te gaan hoe het gaat in de praktijk, dan dat men in theorie zegt of weet. Ik ben geïnteresseerd in jouw mening en vraag jou dan ook om een zo'n eerlijk mogelijk antwoord te geven. Het interview zal 45 tot 60 minuten duren. Mochten er onduidelijkheden zijn tijdens het interview, dan mag je tussendoor altijd om extra uitleg vragen. Neem ook gerust de tijd om na te denken over een antwoord.
Het interview bestaat uit verschillende onderdelen. We starten met een algemeen onderdeel over jou en jouw functie binnen deze organisatie. Vervolgens zullen er een aantal thema's worden behandeld. Tot slot nog enkele vragen over de werkomgeving en is er ruimte voor verdere vragen/opmerkingen. Heb jij verder nog vragen over mijn onderzoek of interview voordat we gaan beginnen?

Persoonlijke achtergrond

Dan wil ik graag eerst even beginnen met wat algemene vragen.

1. Kun je jezelf even kort voorstellen? *(Naam, leeftijd, woonplaats, opleiding)*
2. Hoe lang werk je al in de zorg?
   (Korte beschrijving loopbaan: werken met dementie (hoeveel jaar met dementerenden gewerkt, welk stadia van dementie), werken in verpleeghuizen)

3. Kun je een korte beschrijving geven van je huidige functie?
4. Kun je samen met mij eens een normale werkdag doorlopen, hoe ziet zo'n werkdag eruit? *(Werkzaamheden, activiteiten, samenwerkingen in het team)*

Patiënt participatie:

Het volgende onderdeel van dit interview is opgedeeld in vier verschillende thema's omtrent patiënt participatie. Ik wil graag beginnen met het eerste thema. Als je opmerkingen of vragen hebt mag je deze tijdens of aan het einde van het interview stellen.

Thema 1. Aanbieden en stimuleren van activiteiten

Tijdens het werk kun je verschillende activiteiten aanbieden voor de cliënten. Vaak leggen organisaties de activiteiten en werkzaamheden vast. Echter, kan het aanbieden van activiteiten op vele verschillende manieren worden gestimuleerd. Denk hierbij bijvoorbeeld aan een wandeling maken met een cliënt. Dit kan zowel door de zorgverlener, jijzelf in dit geval, worden gestimuleerd en aangereikt, als door de cliënt zelf worden aangevraagd.

5. Aanbieden dagelijkse bezigheden
   - ➢ Hierbij valt te denken aan het aantrekken van kleding, het kiezen van voedsel, het aanreiken van spelletjes en dergelijke. *Doorvragen of er rekening wordt gehouden van de wensen en behoeften van cliënten.* [providing choices in daily living]
6. Stimuleren van activiteiten
   - ➢ Fysiek [Physical stimulation]
   - ➢ Intellectueel. Hierbij valt te denken aan waarnemen, taal, geheugen, aandacht, en concentratie [Intellectual stimulation]
     Doorvragen naar welke activiteiten, of de cliënten bereid zijn om mee te doen en of er regels/handleidingen zijn opgesteld
7. Nemen cliënten zelf ook het initiatief om actief deel te nemen? Vragen zij bijvoorbeeld wel eens om iets te doen? [Mutual engagement]

Thema 2. Het begrijpen van de cliënten

Het volgende thema gaat over het begrijpen van de cliënt. Tijdens je werk, werk je met 12 verschillende cliënten. Daarbij kan het zijn dat je de ene cliënt beter kent en begrijpt dan de andere cliënt. Daarnaast heeft elke cliënt een ander ziektebeeld en kan gedragsproblematiek ook een rol spelen.

8. Heb jij het idee dat je van ieder cliënt het ziektebeeld kent? *Doorvragen of men weet in welk stadium van dementie de cliënt zich begeeft.* [Understand illness]
9. Beschik je over alle relevante informatie?
   - ➢ Te denken aan levengeschiedenis [history], medische gegevens [understanding illness]. *Doorvragen of er onderscheidt wordt gemaakt tussen de functies betreft de toegang, of men zelfinitiatief neemt om tot de informatie te komen.*
10. Het volledig begrijpen en kennen van de cliënt.
    - ➢ Hierbij te denken aan het begrijpen van de cliënt in verschillende situaties, weten wat de cliënt leuk vindt en wat de cliënt nodig heeft. *Doorvragen of scholing hierbij van belang is* [Understanding

11. Je zou de cliënten kunnen indelen in leefmilieus, wat betekent dat je drie groepen hebt. Stimulerende groep (zorgen voor zelfredzaamheid), structurerende groep (voorkomen van escalaties door gevaar voor overprikkeling) en beschermende groep (creëren van veiligheid en daarbij met intensieve verpleging). Met welke groep zou jij de meeste affiniteit hebben? [Team/ organisation interest]

Thema 3. De relatie tussen zorgmedewerker en cliënt

De relatie tussen patiënt en zorgmedewerker is van groot belang voor het leveren van zorg. Met relatie bedoel ik hier de verstandhouding, oftewel de connectie, relatie of band die je hebt met de dementerende ouderen van jouw afdeling. De volgende vragen gaan over dit thema.

12. Beeld schetsen van de communicatie met dementerende ouderen [communication]
    - Betekenisvol gesprek [meaningful interaction nurse-patient]
    - Rol van scholing
13. De verstandshouding met de cliënten [relationship] [equal]
    a. Wat is voor jouw belangrijk in het opbouwen van een relatie met de cliënten? *Als men geen factoren kan verzinnen, kan er gedacht worden aan de factoren als vertrouwen, respect en onderhandeling.*
14. Ervaar jij problemen of word jij tegengehouden in het opbouwen van een band met cliënten? *(Doorvragen of men voldoende tijd heeft om een relatie op te bouwen en of de collega's hierin stimuleren en of de cultuur hierbij een rol speelt)*

Thema 4. De mate van sturing geven in het leveren van zorg

Het organiseren en het zorgen voor ouderen met dementie kan soms uitdagend zijn en ethische kwesties met zich meebrengen. Hierbij kan je je continue afvragen in hoeverre de autonomie, oftewel de zelfstandigheid, van die cliënten gewaarborgd blijft.
Autonomie, de zelfstandigheid, zorgt ervoor dat ouderen met dementie hun leven kunnen inrichten zoals zij dat willen. Echter, hebben zij ook behoefte aan hulp en zijn zij dus afhankelijk van anderen, zoals familieleden en zorgpersoneel.

15. Hoe ervaar jij deze ethische kwestie: waarbij je aan de ene kant hun zelfstandigheid moet respecteren (dat ze zelf kunnen beslissen) maar aan de andere kant dat zij hulpbehoevend zijn je (en dat ze afhankelijk zijn van jouw hulp)? [Balance dependency and autonomy]
    a. Ervaar je het als gemakkelijk om een juiste balans te vinden tussen de afhankelijkheid en autonomie van cliënten of vind je dit juist moeilijk?
16. Besluitvorming in de zorg [Decision-making process] (*Doorvragen wie er beslissingen neemt, of dementerende ouderen gestimuleerd worden om hun eigen verantwoordelijkheid te nemen) (Concepten als zelfredzaam of zelfstandigheid)*
    a. De rol van de behoeftes en wensen van de cliënten [Shared decision-making]
    b. De rol van familie
17. Mate van sturing geven en een stap terug doen in het werk [take a step back]
    - Hierbij te denken aan hoe geeft men de controle terug aan de cliënten; wie heeft de regie; stapje terug en van een afstand meedoen.

Algemene werkomgeving

Tot zover de verschillende thema's die betrekking hebben op cliënt participatie. Graag zou ik nog enkele vragen willen stellen hoe jij de werkomgeving ervaart over, van, voor het stimuleren van de actieve deelname van jullie cliënten. En daarnaast ook jullie dit binnen het team aanpakken.

18. Ervaar jij verschillen in de manier van aanpak tussen de verschillende functies, zoals gastvrouwen, helpenden, VIG'ers en/of verpleegkundigen als het gaat om cliënt participatie? *Bijvoorbeeld stimuleert een helpende anders dan een gastvrouw doet? Doorvragen waardoor deze verschillen zijn kunnen ontstaan.*
    - De rol van cliënt participatie binnen het team en de organisatie
19. Word jij zelf genoeg gestimuleerd om de cliënten actief te houden? *Doorvragen of men voldoende informatie heeft hoe de cliënten te stimuleren, of er voldoende middelen zijn in de vorm van tijd en cultuur, en of men wordt aangemoedigd binnen het team.*
    - Belemmeringen of facilitators
20. *Indien de participant nog niet de scholing heeft aangehaald, dan de volgende vraag tot slot vragen:* Heb je voor jouw idee voldoende scholing gehad, hoe om te gaan met de dementerende ouderen en hoe hen te stimuleren? *Doorvragen welke specifieke scholing de participant graag wil krijgen en of er nog andere praktische zaken zijn die stimulatie bevorderen.*

Tot slot

Dan ben ik nu aan het einde gekomen van mijn interview. Ik wil jou hartelijk bedanken voor het antwoorden van mijn vragen. Heb je zelf nog toevoegingen, vragen en/of opmerkingen die ik kan meenemen over het stimuleren van jouw bewoners? Wat vond je van het interview?
Nadat ik het interview heb uitgewerkt, zal ik de uitgewerkte versie van jouw interview naar je toesturen. Jij hebt dan de mogelijkheid om deze door te lezen en eventuele opmerkingen toe te voegen via de e-mail. Jij kunt aangeven indien er delen moeten worden aangepast als deze niet herleidbaar zijn. Nadat mijn onderzoek is afgerond, zal ik een presentatie aan het team geven om mijn inzichten te presenteren. Zou je daarnaast nog graag het uiteindelijke onderzoeksrapport, wat in het Engels is geschreven, of een kortere samenvatting in het Nederlands ontvangen? Mocht jij in de tussentijd nog vragen of toevoegingen hebben, dan kun je mij altijd bereiken via de e-mail.

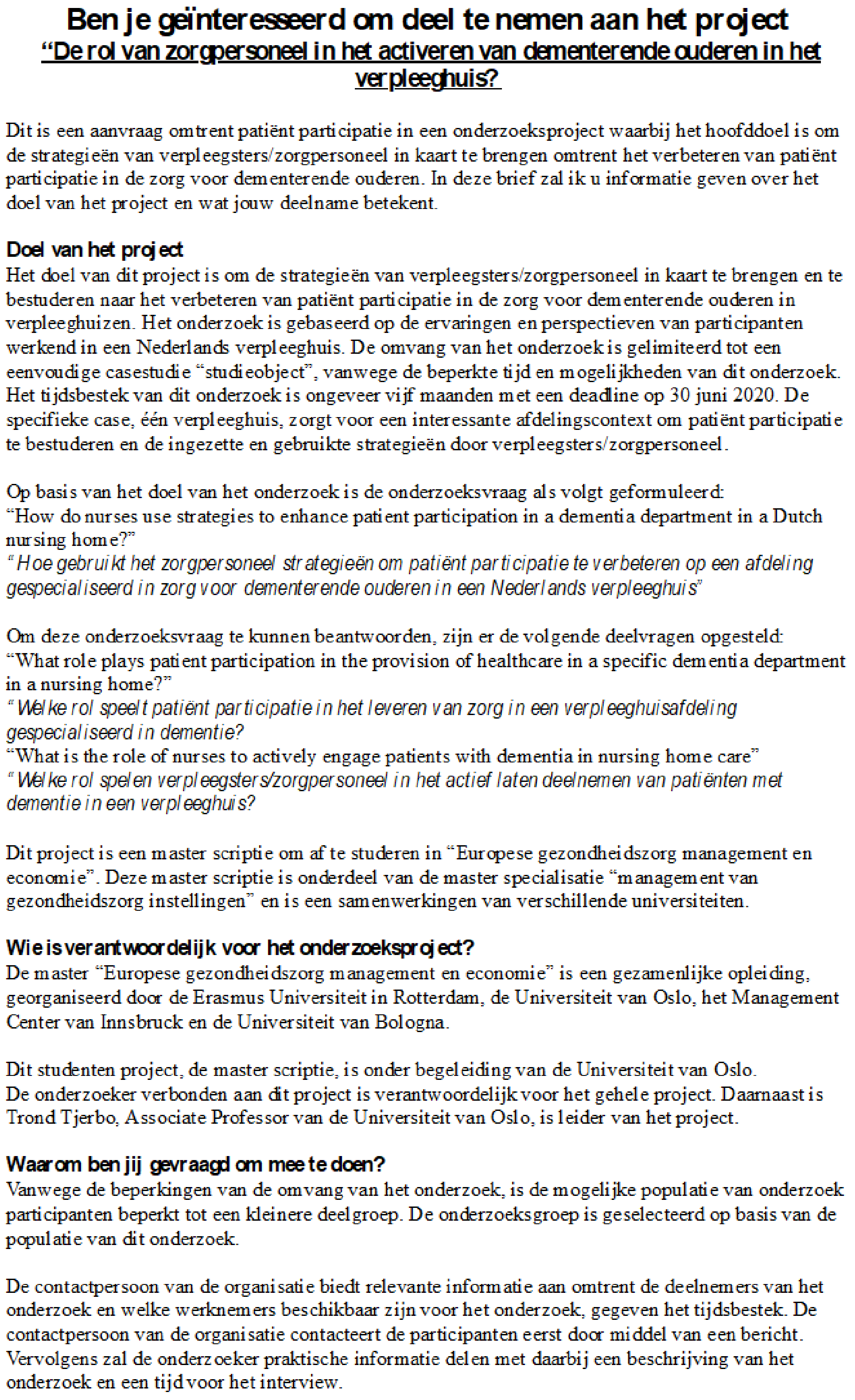
Zou je nog het informatieformulier, en daarbij de toestemming voor het verwerken van jouw antwoorden, willen invullen? Nogmaals hartelijk bedankt voor het meewerken aan mijn onderzoek.

7.2 Appendix B: Overview of professions and core responsibilities

Function (NL)	**Function (EN)**	**Core responsibilities**
Gastvrouw	Healthcare hostess	Mainly responsible for the meals, coffee and tea moments and guidance and support in activities
Helpende	Care assistant (level2)	ADL care which mainly consists of guidance residents to get up, dress, wash, eat and to go to bed.
Verzorgende individuele gezondheidszorg (VIG)	Caregiver individual healthcare (level3)	Different tasks in relation to nurturing, accompanying and medication.
Verpleegkundige MBO	Nurse (level4)	Coordination and provision of healthcare, including intakes and treatment plans.

Table 7.1 Description of the professions and core responsibilities

7.3 Appendix C: Information and request form for participation



Ben je geïnteresseerd om deel te nemen aan het project
"De rol van zorgpersoneel in het activeren van dementerende ouderen in het verpleeghuis?

Dit is een aanvraag omtrent patiënt participatie in een onderzoeksproject waarbij het hoofddoel is om de strategieën van verpleegsters/zorgpersoneel in kaart te brengen omtrent het verbeteren van patiënt participatie in de zorg voor dementerende ouderen. In deze brief zal ik u informatie geven over het doel van het project en wat jouw deelname betekent.

Doel van het project

Het doel van dit project is om de strategieën van verpleegsters/zorgpersoneel in kaart te brengen en te bestuderen naar het verbeteren van patiënt participatie in de zorg voor dementerende ouderen in verpleeghuizen. Het onderzoek is gebaseerd op de ervaringen en perspectieven van participanten werkend in een Nederlands verpleeghuis. De omvang van het onderzoek is gelimiteerd tot een eenvoudige casestudie "studieobject", vanwege de beperkte tijd en mogelijkheden van dit onderzoek. Het tijdsbestek van dit onderzoek is ongeveer vijf maanden met een deadline op 30 juni 2020. De specifieke case, één verpleeghuis, zorgt voor een interessante afdelingscontext om patiënt participatie te bestuderen en de ingezette en gebruikte strategieën door verpleegsters/zorgpersoneel.

Op basis van het doel van het onderzoek is de onderzoeksvraag als volgt geformuleerd:
"How do nurses use strategies to enhance patient participation in a dementia department in a Dutch nursing home?"
"Hoe gebruikt het zorgpersoneel strategieën om patiënt participatie te verbeteren op een afdeling gespecialiseerd in zorg voor dementerende ouderen in een Nederlands verpleeghuis"

Om deze onderzoeksvraag te kunnen beantwoorden, zijn er de volgende deelvragen opgesteld:
"What role plays patient participation in the provision of healthcare in a specific dementia department in a nursing home?"
"Welke rol speelt patiënt participatie in het leveren van zorg in een verpleeghuisafdeling gespecialiseerd in dementie?
"What is the role of nurses to actively engage patients with dementia in nursing home care"
"Welke rol spelen verpleegsters/zorgpersoneel in het actief laten deelnemen van patiënten met dementie in een verpleeghuis?

Dit project is een master scriptie om af te studeren in "Europese gezondheidszorg management en economie". Deze master scriptie is onderdeel van de master specialisatie "management van gezondheidszorg instellingen" en is een samenwerkingen van verschillende universiteiten.

Wie is verantwoordelijk voor het onderzoeksproject?

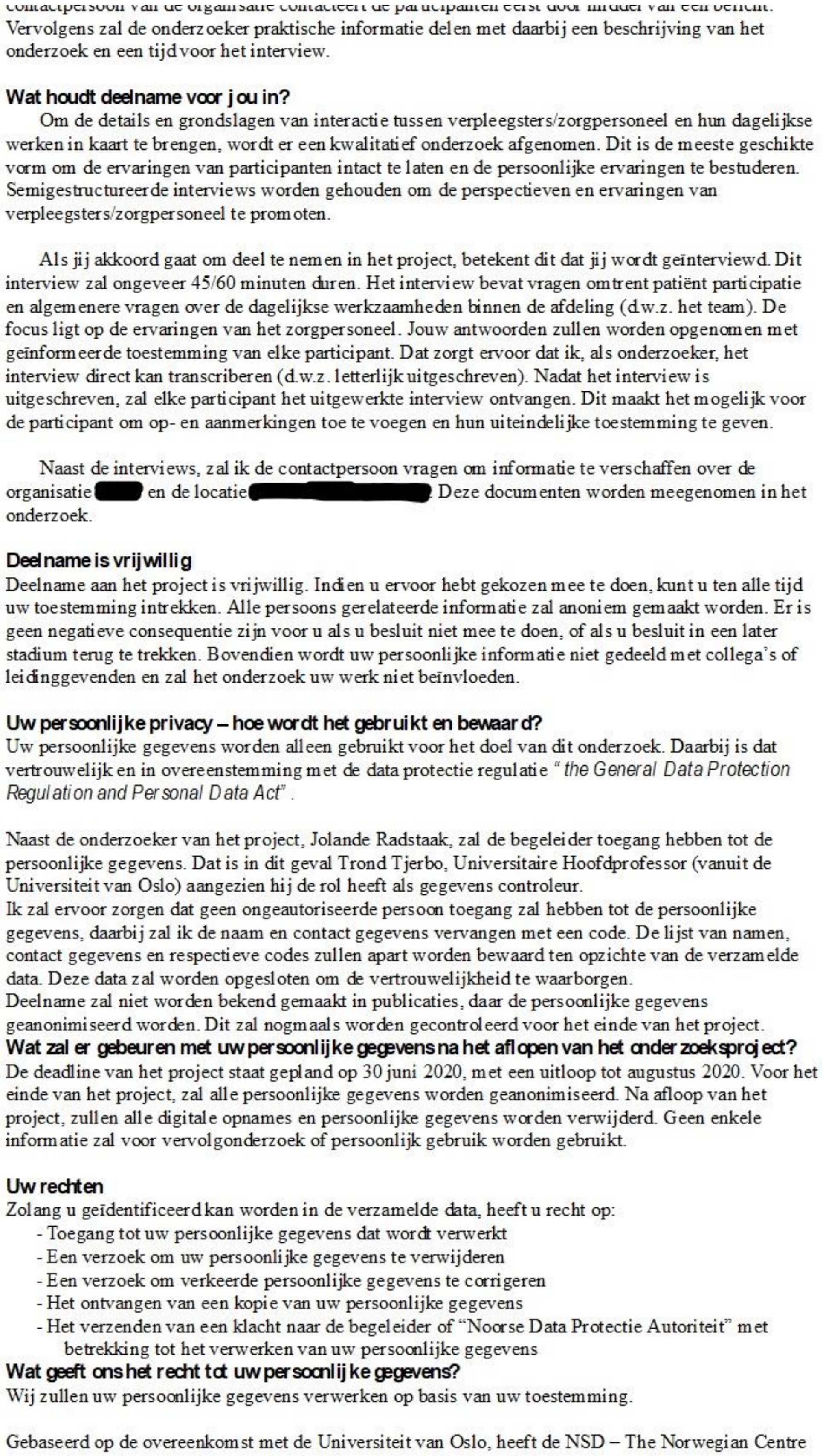
De master "Europese gezondheidszorg management en economie" is een gezamenlijke opleiding, georganiseerd door de Erasmus Universiteit in Rotterdam, de Universiteit van Oslo, het Management Center van Innsbruck en de Universiteit van Bologna.

Dit studenten project, de master scriptie, is onder begeleiding van de Universiteit van Oslo.
De onderzoeker verbonden aan dit project is verantwoordelijk voor het gehele project. Daarnaast is Trond Tjerbo, Associate Professor van de Universiteit van Oslo, is leider van het project.

Waarom ben jij gevraagd om mee te doen?

Vanwege de beperkingen van de omvang van het onderzoek, is de mogelijke populatie van onderzoek participanten beperkt tot een kleinere deelgroep. De onderzoeksgroep is geselecteerd op basis van de populatie van dit onderzoek.

De contactpersoon van de organisatie biedt relevante informatie aan omtrent de deelnemers van het onderzoek en welke werknemers beschikbaar zijn voor het onderzoek, gegeven het tijdsbestek. De contactpersoon van de organisatie contacteert de participanten eerst door middel van een bericht. Vervolgens zal de onderzoeker praktische informatie delen met daarbij een beschrijving van het onderzoek en een tijd voor het interview.



contactpersoon van de organisatie contacteert de participanten eerst door middel van een bericht. Vervolgens zal de onderzoeker praktische informatie delen met daarbij een beschrijving van het onderzoek en een tijd voor het interview.

Wat houdt deelname voor jou in?

Om de details en grondslagen van interactie tussen verpleegsters/zorgpersoneel en hun dagelijkse werken in kaart te brengen, wordt er een kwalitatief onderzoek afgenomen. Dit is de meeste geschikte vorm om de ervaringen van participanten intact te laten en de persoonlijke ervaringen te bestuderen. Semigestructureerde interviews worden gehouden om de perspectieven en ervaringen van verpleegsters/zorgpersoneel te promoten.

Als jij akkoord gaat om deel te nemen in het project, betekent dit dat jij wordt geïnterviewd. Dit interview zal ongeveer 45/60 minuten duren. Het interview bevat vragen omtrent patiënt participatie en algemenere vragen over de dagelijkse werkzaamheden binnen de afdeling (d.w.z. het team). De focus ligt op de ervaringen van het zorgpersoneel. Jouw antwoorden zullen worden opgenomen met geïnformeerde toestemming van elke participant. Dat zorgt ervoor dat ik, als onderzoeker, het interview direct kan transcriberen (d.w.z. letterlijk uitgeschreven). Nadat het interview is uitgeschreven, zal elke participant het uitgewerkte interview ontvangen. Dit maakt het mogelijk voor de participant om op- en aanmerkingen toe te voegen en hun uiteindelijke toestemming te geven.

Naast de interviews, zal ik de contactpersoon vragen om informatie te verschaffen over de organisatie [redacted] en de locatie [redacted]. Deze documenten worden meegenomen in het onderzoek.

Deelname is vrijwillig

Deelname aan het project is vrijwillig. Indien u ervoor hebt gekozen mee te doen, kunt u ten alle tijd uw toestemming intrekken. Alle persoons gerelateerde informatie zal anoniem gemaakt worden. Er is geen negatieve consequentie zijn voor u als u besluit niet mee te doen, of als u besluit in een later stadium terug te trekken. Bovendien wordt uw persoonlijke informatie niet gedeeld met collega's of leidinggevenden en zal het onderzoek uw werk niet beïnvloeden.

Uw persoonlijke privacy – hoe wordt het gebruikt en bewaard?

Uw persoonlijke gegevens worden alleen gebruikt voor het doel van dit onderzoek. Daarbij is dat vertrouwelijk en in overeenstemming met de data protectie regulatie *"the General Data Protection Regulation and Personal Data Act"*.

Naast de onderzoeker van het project, Jolande Radstaak, zal de begeleider toegang hebben tot de persoonlijke gegevens. Dat is in dit geval Trond Tjerbo, Universitaire Hoofdprofessor (vanuit de Universiteit van Oslo) aangezien hij de rol heeft als gegevens controleur.
Ik zal ervoor zorgen dat geen ongeautoriseerde persoon toegang zal hebben tot de persoonlijke gegevens, daarbij zal ik de naam en contact gegevens vervangen met een code. De lijst van namen, contact gegevens en respectieve codes zullen apart worden bewaard ten opzichte van de verzamelde data. Deze data zal worden opgesloten om de vertrouwelijkheid te waarborgen.
Deelname zal niet worden bekend gemaakt in publicaties, daar de persoonlijke gegevens geanonimiseerd worden. Dit zal nogmaals worden gecontroleerd voor het einde van het project.

Wat zal er gebeuren met uw persoonlijke gegevens na het aflopen van het onderzoeksproject?

De deadline van het project staat gepland op 30 juni 2020, met een uitloop tot augustus 2020. Voor het einde van het project, zal alle persoonlijke gegevens worden geanonimiseerd. Na afloop van het project, zullen alle digitale opnames en persoonlijke gegevens worden verwijderd. Geen enkele informatie zal voor vervolgonderzoek of persoonlijk gebruik worden gebruikt.

Uw rechten

Zolang u geïdentificeerd kan worden in de verzamelde data, heeft u recht op:

- Toegang tot uw persoonlijke gegevens dat wordt verwerkt
- Een verzoek om uw persoonlijke gegevens te verwijderen
- Een verzoek om verkeerde persoonlijke gegevens te corrigeren
- Het ontvangen van een kopie van uw persoonlijke gegevens
- Het verzenden van een klacht naar de begeleider of "Noorse Data Protectie Autoriteit" met betrekking tot het verwerken van uw persoonlijke gegevens

Wat geeft ons het recht tot uw persoonlijke gegevens?

Wij zullen uw persoonlijke gegevens verwerken op basis van uw toestemming.

Gebaseerd op de overeenkomst met de Universiteit van Oslo, heeft de NSD – The Norwegian Centre

Gebaseerd op de overeenkomst met de Universiteit van Oslo, heeft de NSD – The Norwegian Centre for Research Data AS- bepaald dat verwerking van persoonlijke gegevens in overeenstemming is met de data protectie regulatie.

Waar kan ik meer informatie vinden?

Als u vragen hebt over het project of als u uw rechten wilt uit oefen, contact:

- Jolande Radstaak (student onderzoeker), via email: jolanderadstaak@hotmail.com of via telefoon: +31628967661
- Universiteit van Oslo via de project begeleider Trond Tjerbo, via email: trond.tjerbo@medisin.uio.no of via telefoon: + 4722845362
- NSD – Het Noorweegse Cetrum voor Onderzoeks Data, via email: (personverntjenester@nsd.no) of via telefoon: +47 55 58 21 17.

Met vriendelijke groet,

Projectleider (supervisor) Student

Toestemming formulier

Ik heb alle informatie ontvangen en begrepen omtrent het project "De rol van zorgpersoneel in het activeren van dementerende ouderen in het verpleeghuis" en heb de mogelijkheid gekregen om vragen te stellen. Ik geef toestemming:

☐ Om deel te nemen aan het project
☐ Om deel te nemen aan het interview
☐ Om mijn persoonlijke gegevens te anonimiseren zodat ik niet kan worden herkend
☐ Om mijn informatie te gebruiken voor data-analyse ten aanzien van het onderzoek

Ik geef toestemming om mijn persoonlijke gegevens te verwerken tot aan het einde van het project, ongeveer eind augustus 2020.

(Getekend door participant, datum)

7.4 Appendix D: Code tree

Patient participation in specialized dementia care units

1. **Active engagement in activities**
    - 1.1. Meaningful activities
        - 1.1.1.Social
        - 1.1.2.Physical
        - 1.1.3.Intellectual
        - 1.1.4.Leisure [games]
        - 1.1.5.Tools and guidelines
        - 1.1.6.Willingness of residents
    - 1.2. Active mutual engagement
        - 1.2.1.Initiative by the patient
        - 1.2.2.Initiative by the healthcare personnel
    - 1.3. Activation/Stimulation
        - 1.3.1.Verbal motivation by the healthcare personnel
    - 1.4. Balance between individuals and group activities
2. **Relationship between healthcare personnel and patient**
    - 2.1. Interaction between personnel and patient
        - 2.1.1.Equal relationship
        - 2.1.2.Meaningful dialogue
        - 2.1.3.Communication with dementia residents
            - 2.1.3.1. Listen to the individual’s need
            - 2.1.3.2. Recognition on the part of the nurse of patients as individuals
    - 2.2. Beliefs and values that underpin relationships
        - 2.2.1.Respect
        - 2.2.2.Trust
        - 2.2.3.Negotiation
        - 2.2.4.Empathy
        - 2.2.5.Equality
3. **Understanding the patient**
    - 3.1. Understanding illness
        - 3.1.1.Available (medical) patient information
        - 3.1.2.Access to (medical) patient information

    - 3.1.3.Tools and guidelines
    - 3.1.4.Understanding of dementia
        - 3.1.4.1. Knowledge of dementia within the team
  - 3.2. Understanding the resident
    - 3.2.1.Preferences, interests and hobbies
    - 3.2.2.Behaviour (abnormalities) of the patient
  - 3.3. Connection with the patient
    - 3.3.1.Picking up signals
    - 3.3.2.Retain a sense of humanness
  - 3.4. Personal medical history of the patient

4. The degree of control healthcare professionals give over to the residents

  - 4.1. Recognition of the patient’s responsibility
    - 4.1.1.Responsibility of the residents
    - 4.1.2.Request patient’s wishes and needs
  - 4.2. Balance between accepting dependency on others and maintaining a sense of autonomy
    - 4.2.1.Independency of residents
    - 4.2.2.Directing the residents
        - 4.2.2.1. Taking over residents’ tasks
        - 4.2.2.2. Remain in control of care
        - 4.2.2.3. Take a step back
    - 4.2.3.Dependency of residents
  - 4.3. Decision-making process in the caregiving
    - 4.3.1.Involvement of healthcare personnel in the decision-making
        - 4.3.1.1. Making decisions on behalf of the patient
        - 4.3.1.2. Providing choices for the patient to decide
    - 4.3.2.Involvement of patient in the decision-making
    - 4.3.3.Involvement of family or relatives in the decision-making

5. How healthcare professionals influence patient participation

  - 5.1. Attitude and behaviour of healthcare professionals
  - 5.2. Different mechanisms influencing healthcare professionals
    - 5.2.1.Organizational influencing patient participation
    - 5.2.2.Team features influencing patient participation
    - 5.2.3. Contextual features influencing patient participation

7.5 Appendix E: Code list

- Ability to understand information
- Accepting patient's wishes
- Access to patient information
- Active attitude in work
- Activities
- Activities plan
- Additional tasks to complete
- Affectionate love for residents
- Aggression among patients
- Amount of personnel
- Appreciation of work flexibility
- Approaching residents
- Ask residents what they prefer to do
- Atmosphere workplace
- Attitude towards coercion in care
- Attitude towards patient participation
- Available (medical) patient information
- Balance group vs. individual
- Behavioural abnormalities
- Being humble as a healthcare professional
- Being patient as a healthcare professional
- Book on dementia
- Building self-confidence
- Cabinet with leisure activities
- Care decision-making
- Coaching colleagues
- Coercion in care
- Cognitive activities
- Collaboration with different disciplines
- Commitment to the department
- Conflict between patient and carer
- Dealing with own work
- Dealing with the resident
- Decision-making on behalf of the resident
- Decision-making during intake
- Dedication to own profession
- Department facilities
- Dependency resident
- Differences between colleagues
- Directing the resident
- Discrepancy in practice
- Disregard patient's wishes
- Documentation of information
- Education dementia
- Electronic Health Record
- Emotion-oriented care
- Empathy in establishing relationships
- Equality in establishing relationships
- Equality within communication
- Equality within the team
- Expectation based on trust
- Expectation of colleagues
- Experienced facilitators to patient participation
- Experienced hindrances to patient participation
- Family as a source of information
- Family setting living room
- Feedback from colleagues
- Flexibility to adapt work if patient disagrees
- Former inequality at the workplace
- Hierarchy
- History of patient
- Independency resident
- Initiative patient
- Initiative health care personnel
- Inviting residents in activities
- Involvement of family in decision-making
- Involvement of healthcare personnel in decision-making
- Involvement of residents in care decisions
- Job satisfaction
- Knowing the patient
- Knowledge on dementia
- lack of dementia training
- Lack of guidelines for activities
- Lack of guidelines on behavioural abnormalities
- Lack of guidelines on stimulation
- Lack of knowledge
- Lack of resources
- Learning from colleagues
- Learning from own personal network
- Learning over time
- Leisure (games) activities

- Limited time
- Listening to resident
- Live environments
- Manuals and activities
- Meaningful dialogue
- Mutuality between residents
- Need for dementia training
- Need for knowledge
- Need for team training
- Non-verbal communication
- Observation
- Opportunity to build a relationship
- Organizational culture
- Organizational structure
- Organizational vision
- Participation and phases of dementia
- Passivity colleagues
- Passivity residents
- Patient's ability to express wishes
- Perceived workload
- Perception of time
- Physical activities
- Picking up signals
- Proactive attitude of SPN
- Provide distraction
- Providing activities for residents
- Providing choices for residents
- Provision of activities
- Read all patient's information
- Recognition of resident
- Recognition of staff members
- Relationship nurse-patient
- Remain in control
- Remain calm in work
- Reporting
- Resident’s dignity
- Resident’s interests and hobbies
- Resident’s needs
- Residents' structure
- Residents' urgency to feel useful
- Respect in establishing relationships
- Responsibility VIG
- Role of team supervisor
- Safety in establishing relationships
- Self confidence
- Self-reflection
- Sense residents
- Shared vision
- Signals dementia
- Social activities
- Social Welfare Employees
- Sparring with colleagues
- Specialized Psychogeriatric Nurse
- Stimulation in the team
- Stimulation residents by impulses
- Stimulation residents in general
- Stimulation residents with nutrition
- Stimulation: extra time
- Structure in performing job
- Supportive team
- Take a step back
- Take the time
- Task oriented nursing labour
- Task responsibility
- Team meetings
- Time on duty
- To be yourself
- To come up with an activity
- To take over of the patient
- Training in dementia (care)
- Training in providing care
- Traits of healthcare professionals
- Transmission of information
- Trust in establishing relationships
- Understanding the disease
- Using previous work experience
- Verbal communication
- Verbal motivation
- Willingness team
- Work environment
- Work experience
- Work flexibility

7.6 Appendix F: Approval from NSD

NSD NORSK SENTER FOR FORSKNINGSDATA

NSD's assessment

Project title

Master Thesis on nursing strategies and the impact on patient participation in nursing homes

Reference number

516742

Registered

03.12.2019 av Jolande Janique Radstaak - jolander@uio.no

Data controller (institution responsible for the project)

Universitetet i Oslo / Det medisinske fakultet / Institutt for helse og samfunn

Project leader (academic employee/supervisor or PhD candidate)

Trond Tjerbo, trond.tjerbo@medisin.uio.no, tlf: 004722845362

Type of project

Student project, Master's thesis

Contact information, student

Jolande Radstaak, jolanderadstaak@hotmail.com, tlf: 0031628967661

Project period

01.01.2020 - 01.09.2020

Status

17.02.2020 - Assessed

Assessment (2)

17.02.2020 - Assessed

NSD has assessed the change registered on 15.02.2020.

New end date for processing of personal data is set to 01.09.2020.

We find that the processing of personal data in this project will comply with data protection legislation, so long as it is carried out in accordance with what is documented in the Notification Form and attachments, dated 17.02.2020. Everything is in place for the processing to continue.

FOLLOW-UP OF THE PROJECT
NSD will follow-up the project at the planned end date in order to determine whether the processing of personal data has been concluded.

Good luck with the project!
Contact person at NSD: Karin Lillevold
Data Protection Services for Research: +47 55 58 21 17 (press 1)

14.02.2020 - Assessed

Our assessment is that the processing of personal data in this project will comply with data protection legislation, presupposing that it is carried out in accordance with the information given in the Notification Form and attachments, dated 14.02.2020, as well as in dialogue with NSD. Everything is in place for the processing to begin.

NOTIFY CHANGES
If you intend to make changes to the processing of personal data in this project it may be necessary to notify NSD. This is done by updating the information registered in the Notification Form. On our website we explain which changes must be notified. Wait until you receive an answer from us before you carry out the changes.

TYPE OF DATA AND DURATION
The project will be processing general categories of personal data until 01.07.2020.

LEGAL BASIS
The project will gain consent from data subjects to process their personal data. We find that consent will meet the necessary requirements under art. 4 (11) and 7, in that it will be a freely given, specific, informed and unambiguous statement or action, which will be documented and can be withdrawn. The legal basis for processing personal data is therefore consent given by the data subject, cf. the General Data Protection Regulation art. 6.1 a).

PRINCIPLES RELATING TO PROCESSING PERSONAL DATA
NSD finds that the planned processing of personal data will be in accordance with the principles under the General Data Protection Regulation regarding:

- lawfulness, fairness and transparency (art. 5.1 a), in that data subjects will receive sufficient information about the processing and will give their consent
- purpose limitation (art. 5.1 b), in that personal data will be collected for specified, explicit and legitimate purposes, and will not be processed for new, incompatible purposes
- data minimisation (art. 5.1 c), in that only personal data which are adequate, relevant and necessary for the purpose of the project will be processed
- storage limitation (art. 5.1 e), in that personal data will not be stored for longer than is necessary to fulfil the project’s purpose

THE RIGHTS OF DATA SUBJECTS
Data subjects will have the following rights in this project: transparency (art. 12), information (art. 13), access (art. 15), rectification (art. 16), erasure (art. 17), restriction of processing (art. 18), notification (art. 19), data portability (art. 20). These rights apply so long as the data subject can be identified in the collected data.

NSD finds that the information that will be given to data subjects about the processing of their personal data will meet the legal requirements for form and content, cf. art. 12.1 and art. 13.

We remind you that if a data subject contacts you about their rights, the data controller has a duty to reply within a month.

FOLLOW YOUR INSTITUTION’S GUIDELINES
NSD presupposes that the project will meet the requirements of accuracy (art. 5.1 d), integrity and confidentiality (art. 5.1 f) and security (art. 32) when processing personal data.

To ensure that these requirements are met you must follow your institution’s internal guidelines and/or consult with your institution (i.e. the institution responsible for the project).

FOLLOW-UP OF THE PROJECT
NSD will follow up the progress of the project at the planned end date in order to determine whether the processing of personal data has been concluded.

Good luck with the project!

Contact person at NSD: Karin Lillevold
Data Protection Services for Research: +47 55 58 21 17 (press 1)