PERSON-CENTERED DEMENTIA CARE:

- From Care Theory to Care Practice -

How do health personnel and management understand and enact
person-centered dementia care in Norwegian nursing homes?

Written by Hedda Olesen Arfaoui

Supervisor Benedikte Victoria Lindskog
Co-supervisor Anne Marie Mork Rokstad

UiO | UNIVERSITY OF OSLO

Department of Community Medicine
Institute of Health and Society
The Faculty of Medicine

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ABSTRACT

Person-centered care has been described as the best way to care for someone with dementia. This approach to care is now on the Norwegian political agenda and is included in mission statements and job descriptions of increasingly many nursing homes. However, it is still unclear whether this way of caring for someone with dementia is actually applied in nursing homes on a daily basis and how much knowledge and training health professionals working in long-term care facilities have on the subject. The present qualitative study is an exploration of the practice and implementation of person-centered care in the context of two Norwegian nursing homes with a person-centered care vision. Through the use of in-depth interviews and observations this study has explored the ways in which person-centered care is understood, enacted or resisted across levels of staff in the daily context of long-term care in Norway. As such, this study uncovered findings related to staff's understanding and knowledge of person-centered care, the ways in which their understanding was translated into individual practice, but also what challenges they encountered in the implementation of person-centered care. The study reveals a piecemeal practice and implementation of person-centered care, despite the institutions' commitment and a staff relatively familiar with the underlying principles and values of this care approach. By providing insight into the reality of dementia care in Norwegian nursing homes, and shedding light on the competing demands and values that shape care practices, the findings of this research contribute to the mounting literature on person-centered care implementation in Norway.

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LIST OF ABBREVIATIONS

PCC:	Person-centered care
PCDC:	Person-centered dementia care
PPW:	Positive Person Work
MSP:	Malignant Social Psychology
WHO:	World Health Organization
DCM:	Dementia Care Mapping
VPM:	VIPS Practice Model
NPM:	New Public Management
QoL:	Quality of life

INTRODUCTION:

PERSON-CENTERED DEMENTIA CARE

- FROM CARE THEORY TO CARE PRACTICE -

> Although I had been there several times now, today felt a little different. Today, I was given a quick tour of the actual care unit I would be joining once my fieldwork starts. I felt like I was stepping away from the administrative façade that I had gotten to know – with its reception, meeting room and offices – into another realm, unfamiliar and unknown. Sort of like a retail space, if you were to move from the storefront – eye-catching and accessible – to the back room, concealed behind the counter and still unexplored. How different would it be? To my surprise, not that different, it turned out. Indeed, the welcoming entrance, the large windows overlooking the garden, and the long pleasantly furnished corridor that I had gotten to know during my first visits, were not exclusive features of the administrative section. In fact, this rather pleasant layout seemed to extend into some of the wards. Behind a door locked with a code, I discovered a large communal area; this was the dining room, and the living room… in this corner a small open kitchen, in that corner a bar counter. A piano here, a vase there, a tv against the wall. In front of me, another long corridor, with a sequential row of doors on one side (residents room I imagine), and on the other side, top to bottom windows overlooking the garden. The corridor, albeit a little bare, was brightened up by the light coming from the large windows. Some tables and chairs were placed along the wall. I followed my guide as we walked into the care unit's office. There were some people in there, at least two, possibly three. I was so nervous, I don't remember. I was introduced to them, and shortly explained the purpose of my project. One responded with silence, another one asked me if I was a nurse. I told her no, and again, I was met with silence.
>
> (Excerpt from field notes, Peaceful Gardens, Sept. 2017)

The passage above was taken from one of the early entries in my field notes to illustrate the first study site, which for the purpose of anonymity, I will refer to in this thesis as *Peaceful Gardens*. Here, during the fall of 2017, began my meeting with the not-so-unfamiliar world of dementia and dementia care. My interest in dementia began some years back, as I was finishing up my degree in Global Health and Psychology at the University of Toronto. An opportunity for service-learning came about, and I suddenly found myself volunteering in a nursing home, providing company to one of their residents with dementia. Dementia was not completely unknown to me – I have a grandfather who has dementia – but this was new territory, different from what I had previously encountered. This experience stayed with me for several reasons. For one, making contact with a person whom I had never met before, and see that connection flourish over the months is invaluable in itself. Second, as much as I liked going there to visit my new friend, there was something about the state of the place, both in its physical and social form, that bothered me. It was just not adequate, not adapted, not right. And finally, it was during this time that I was introduced to the work of Tom Kitwood, and the alternative lens through which one could, and which I now believe one should, view dementia and the person affected by it. Person-centered care (PCC) was first introduced to the field of dementia by Tom Kitwood in the 90s, and today, this term can be found not only in the literature on dementia care, but also included in a range of official documents and guidelines, dementia plans, and mission statements (Brooker & Latham, 2016). This holistic model of care recognizes the need for a shift in the culture of dementia care; from a purely medical and task-based approach focused on the disease, to an approach that emphasizes the agency and subjective experiences of the person behind the diagnosis (Kitwood, 1997). Now, a few years later, I can finally make use of this conceptual framework in my own work, as I explore the knowledge and enactment of person-centered care within the daily context of dementia care in Norwegian nursing homes.

Indeed, in recent decades, person-centered care has been described as the best way to care for someone with dementia (Brooker & Latham, 2016; Kitwood, 1997; WHO, 2017b) and the care approach is now a central theme within the International and Norwegian political agenda (Norwegian Ministry of Health and Care Services, 2015; WHO, 2017b). In theory, nursing homes in Norway should be aligned with this approach, but, despite undeniable progress, the ever-so-often alarming stories in the media and the constant public debates surrounding sub-standard care in nursing homes suggest that the implementation of this model of care remains insufficient. With this in mind, I wished to undertake a qualitative study, to gain insight into the reality of person-centered dementia care in nursing homes. The flow of the thesis begins with an overview of the field of dementia and dementia care, to situate my study in the wider context of dementia care research. In this chapter I review the main approaches to the field – biomedical and psychosocial – and go deeper into Kitwood's theoretical developments of person-centered care, and discuss the relevant writings and research that have followed. Chapter Two provides a detailed description of the methodology of the study and the data analysis that was undertaken. Chapter Three and Chapter Four is where I lay out my findings and thematic discussions and unveil the reality of translating a care theory into care practice. Chapter Three is concerned with the meaning of person-centered care, how it was understood by the staff I observed and interviewed, and the strategies through which they translated their knowledge into individual practice. Chapter Four builds on the previous chapter, to describe the fragmented institutional practice of person-centered care, and the challenges encountered in the systemic implementation of person-centered care. This chapter reveals a number of challenges – at the individual, organizational and national level - that impact the care practices in institutions. The final chapter is where I summarize my main findings and reflect on the reality of person-centered care provision in the wider context of shifting care expectations and ideals.

At this point, a brief overview of the research setting is warranted. In order to properly address my research question, I felt it was important to get a first-hand experience of the day-to-day life on a dementia ward. The first three months of fieldwork were spent at *Peaceful Gardens*, a municipal nursing home in the Oslo area. The home was divided into two main wards, each subdivided into four smaller units. In an attempt to eliminate aspects of institutionalization, the units were arranged to reflect a home-like environment, and organized around common household tasks. For instance, each unit was responsible for getting groceries from a little convenience store in the basement, and preparing food each day. They were also in charge of doing laundry. Staff were encouraged to involve residents in these activities. The bulk of my fieldwork took place in one of the care units, which was home to eight residents. Staff typically consisted of one care assistant and one nurse, with the latter sometimes joined by a nursing student.

The last month of my fieldwork was spent in another municipal nursing home in Oslo, referred in this study as *Bay Views*. In contrast with the first place, this nursing home included both somatic care units and dementia care units, and thus was home to significantly more residents. The two institutions also diverged in the way they were laid out and organized. Rather than being divided into smaller care units, these wards were bigger, with more residents and staff. Meals too, were organized differently. For instance, dinner was prepped in a large centralized production kitchen in the basement, picked up by staff, before being heated up again and plated. This time I would be joining a dementia ward which was home to twenty-four residents. They were usually seven or eight people working a day shift, usually consisting of care assistants or non-skilled part-time workers, and one nurse, with fewer staff during the evening and night shifts. For practical purposes, the ward was divided into two main 'areas'; residents with rooms on the northern side of the ward would have their meals served in the main dining room, while residents on the southern side would convey to a smaller dining room during meals. Here follows a passage taken from my field notes to illustrate the setting at *Bay Views*:

> Today was the first official day and although I had been here once before, I think it might take me some time to feel completely oriented. I took the elevator up, and for a brief second, I wasn't sure whether to go left or right. I think it's the layout – with those identical corridors –that makes it a little difficult in the beginning. I've been thinking about how this layout may affect the

> residents here (Is it really suitable?). The best way to describe it would be two rectangles positioned next to each other, connected along their shorter side. And in each rectangle, there are 12 resident rooms. The long sides of the rectangles are the corridors, with resident rooms, shower rooms and smaller living rooms. Someone told me that most of the furniture in those living rooms was donated by the residents' families. That's quite neat. In front of each resident room, there's a charming blue-painted mailbox hanging on the wall. I can't help but wonder if they are still in use? (I should ask someone). Where those rectangles meet, in the middle there, there's the office and the elevators. There's also the main communal area, with dining tables, a living room, a small kitchen and a balcony. There are plants and vases spread alongside the window seal. One thing I wasn't expecting, is the beautiful view from here; if I stand in front of the windows and I turn my head to the left, there's Oslo. If I look to the right, there's the fjord.
>
> (Excerpt from field notes, Bay Views, Nov. 2017)

The present qualitative study is an exploration of the practice and implementation of person-centered care at *Peaceful Gardens* and *Bay Views*. Through the use of observations and in-depth interviews with health personnel, the study aims to provide an in-depth understanding of the ways in which person-centered care theory is understood, enacted or resisted across different levels of staff within the daily context of dementia care in Norwegian nursing homes.

CHAPTER ONE:

BACKGROUND AND LITERATURE REVIEW

1.1 BURDEN AND EPIDEMIOLOGY OF DEMENTIA

In 2012, the WHO published a report entitled "Dementia: a Public Health Priority" in which research into dementia is advocated as a priority area of action. In the report, dementia is described as "one of the major causes of disability and dependency among older people" (WHO, 2012, p. 2) with devastating psychological, social, emotional and economic consequences for families, caregivers and communities worldwide. Although not considered a normal part of ageing, dementia most commonly affects persons over the age of 65 (WHO, 2017b). As the world's older population continues to grow at an alarming rate, so does the proportion of people with dementia, with a current yearly incidence of 7.7 million people (WHO, 2012). According to the WHO, 47 million people are currently suffering from dementia, with this number projected to triple by 2050 (WHO, 2017b). As such, dementia represents one of the leading causes of disability and dependency among older adults worldwide, with an estimated 5% to 8% of persons over the age of 60 suffering from dementia (WHO, 2017a). Young onset dementia (defined as onset of dementia before age 65), represents 9% of all cases of dementia (WHO, 2017b). The WHO estimated the total global costs related to dementia in 2010 to US$ 604 billion (WHO, 2012).

Norway too, is seeing a growing incidence of dementia as a result of increased life expectancy (Norwegian Directorate of Health and Social Affairs, 2007). Although no precise prevalence studies exist, the situation in Norway seems to be mirroring what is happening worldwide. It is estimated that approximately 1.5% of the population have dementia, with more than 77000 people diagnosed in 2012 (Norwegian Ministry of Health and Care Services, 2008; Norwegian Ministry of Health and Care Services, 2015). The number of cases is predicted to double by 2040 (Norwegian Directorate of Health and Social Affairs, 2007; Norwegian Ministry of Health and Care Services, 2015). Moreover, over 80% of people living in nursing homes have some form of dementia, making it extremely important to raise competence in dementia and dementia care for professional caregivers working within institutional care (Norwegian Ministry of Health and Care Services, 2015). The Norwegian Directorate of Health and Social Affairs estimated that the future cost of dementia was projected to rise from 14 billion Norwegian kroners per year in 1995 to 18 billion Norwegian kroners in 2020

(Norwegian Directorate of Health and Social Affairs, 2007). Another study reported in the Norwegian Dementia Plan 2020, estimated that the total cost to society could reach almost 30 billion Norwegian Kroners per year (Norwegian Ministry of Health and Care Services, 2015). According to the Dementia Plan 2020, the rising number of people with dementia will have profound consequences for the municipal health and care services. With an increasing burden and no treatment available, more research is greatly needed in all realms of the field (WHO, 2012). However, as the Norwegian Dementia Plan 2020 also notes: "Since a cure for dementia is unlikely to be found in the near future, it is also important to research measures that can delay the onset or the development of dementia and mitigate its consequences" (Norwegian Ministry of Health and Care Services, 2015, p. 19). Measures such as expanding knowledge and competence in dementia care through training programmes and research has therefore been highlighted as one of the priority areas within the Norwegian political agenda (Norwegian Ministry of Health and Care Services, 2008; Norwegian Ministry of Health and Care Services, 2015).

1.2 PERSPECTIVES ON DEMENTIA

1.2.1 Biomedical perspectives vs. Psychosocial perspectives

Dementia is a condition characterized by "deterioration in cognitive function beyond what might be expected from normal ageing" (WHO, 2017a)[1], and severe enough that it interferes with the ability to carry out activities of daily living (WHO, 2017b). The condition is caused by a variety of diseases that affect the brain and is usually progressive, chronic and irreversible in nature (WHO, 2012). The most common type of dementia is Alzheimer's disease, which accounts for 60%-70% of all cases of dementia (WHO, 2017b), but other common types of dementia include vascular dementia, frontotemporal dementia, mixed dementia and dementia with Lewy bodies (Ministry of Health and Care Services, 2015; WHO, 2012). The primary symptom of the deterioration in cognitive function is a loss of memory, often accompanied by deterioration in emotional and social behaviour, as well as functional decline (Norwegian Ministry of Health and Care Services, 2015; WHO, 2012). Other symptoms include "speech loss, difficulties with special orientation and communication [...] anxiety, depression, hallucinations and apathy" (Norwegian Ministry of Health and Care Services, 2015, p. 9). The

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[1] WHO factsheet 2017 retrieved from http://www.who.int/news-room/fact-sheets/detail/dementia

WHO divides dementia into three distinct stages of neuropathological deterioration, with late stage dementia culminating in a state of extreme dependence, loss of psychomotor skills and overall inactivity (WHO, 2017a).

Penrod et al. (2007) explain that two paradigms – biomedical and phenomenological – are presently used to frame and address dementia, “generating distinct bodies of knowledge about living with dementia and related care” (p. 59). Biomedical approaches have resulted in rapid growth and advancement in dementia research in areas such as early diagnosis and development of new drugs for prevention and treatment (Ballenger, 2006; Penrod et al., 2007). However, these advances are almost “exclusively targeted at the use and development of medications and towards preserving the intact body” (Penrod et al., 2007, p. 65). According to the authors, this perspective, which largely focuses on mind-body dualism, shifts the focus of care towards physical and bodily needs, and in doing so, “poses serious challenges to holistic nursing care” (Penrod et al., 2007, p. 66).

The phenomenological paradigm however, largely influenced by psychosocial perspectives, offers contrasting understandings of dementia that have been gaining ground over the last decades. Kitwood (1997) for instance, rejected the reduction of dementia into predetermined stages of disease progression, maintaining that how dementia emerges clinically and how it is experienced by a person, depends on a combination of factors, including personality, biography, physical health, neuropathology and the socio-psychological environment (Brooker & Latham, 2016; Epp, 2003). This alternative way for conceiving of dementia, termed the “Enriched Model of Dementia”, challenges the assumption inherent in the medical model that “dementia could be understood simply by the degree of loss of brain cortex” (Brooker & Latham, 2016, p. 19), and instead invites the possibility of a condition that can, to a certain degree, be shaped by other means than those promised by biomedicine alone (Brooker & Latham, 2016; Kitwood, 1997; Moser, 2008, 2011).

In his work, Tom Kitwood critiques the medicalization of dementia and its reduction to “a merely biological problem to be solved by some kind of technical intervention” (Kitwood, 1997, p. 44). Rather, Kitwood provides a paradigmatic shift that frames symptoms of dementia as not only the result of neuropathological changes in the brain, but also as emerging from changes in the social-psychological environment surrounding the person with dementia. The theory is partly based on the observation that an abnormally rapid loss of abilities occurs following a move to a residential care facility, suggesting that factors other than neuropathic processes are at play. According to Kitwood’s theoretical approach, malignant factors in the care environment are integral to the process of decline linked to dementia and can be positively reshaped to offset this deterioration (Brooker & Latham, 2016; Kitwood, 1997). Understanding the complex interaction between these factors can serve to illuminate and guide practices of care.

1.2.2 The loss of self or the continuity of self

The issue with the medical model of dementia, as Innes (2002) explains, is that it offers a narrative whereby "attention is placed on the hopelessness of the conditions [...] and can lead to the conclusion that the experience of dementia 'is a living death'" (p. 484). An essay written by Taylor (2008, p. 321) about her mother with dementia powerfully captures the implications that this perspective has for the person with dementia:

> It is as if someone with dementia never *could* any longer be part of any story that might continue— and if the life *story* is over, then the life must be over too. More than once, some compassionate interlocutor has remarked to me how difficult it must be to have lost both my father and my mother. I find myself having to insist: "But I have not lost my mother, she is not dead."

According to Kitwood (1997), the agreed-upon and narrow conception of the dementing condition as a "death that leaves the body behind" (p. 37) poses a central problem for the delivery of good care, in that the uniqueness of subjective experiences of dementia is ignored. Hence, Kitwood recognizes the need for a shift in the culture of dementia care, from a purely medical and task-based approach to a person-centered approach (Kitwood, 1997). Central to this approach is the idea that caregivers should strive to maintain a person's 'personhood' throughout the disease process.

The focus of this thesis is on person-centred care and it is therefore vital to say something about the term 'personhood'. Kitwood's definition of personhood places emphasis on relationships and social interaction, as he writes that personhood is "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood, 1997, p. 8). However, other definitions of the term exist in the literature on dementia. Leibing (2006) for instance, describes 'personhood' as referring to "the person within – the reflexive, immaterial, communicable essence of a person that is located deep within the body, but that is sometimes veiled by symptoms" (p. 243). Brooker and Latham (2016) define 'personhood' as "what makes us essentially human. It is what human beings recognize in each other" (p. 18). Moreover, as Dewing (2008) remarks, 'personhood' is ascribed different meanings depending on the body of literature in which it is used, but it is usually defined in terms of the fundamental attributes that make a person. Hence, descriptions and conceptualizations of ‘personhood’ will vary depending on which attributes are emphasized or valued when given the status of ‘person’. Dewing (2008) concludes that “there are consequences in choosing any definition of personhood” (p. 11). For instance, with an emphasis on cognition and memory as valued attributes in western culture, other non-cognitive attributes of personhood, such as “the ability to feel and express emotion and spirituality” (Dewing, 2008, p. 6) risk being disregarded. Similarly, Castillo (2011) argues for the existence of several aspects of personhood, including (but not limited to) cognitive personhood, relational personhood, spiritual personhood and embodied personhood, and maintains that “models of cognitive personhood create excess disability by overvaluing achievement and cognitive function as essential to personhood” (p. 285). Some of these notions of ‘personhood’ will be returned to in the next chapters.

The main argument related to personhood in the context of person-centered care is this: Personhood goes beyond cognition, in that the loss of cognitive abilities and memory does not entail the loss of the person; as such, personhood, despite dementia, persists. Person-centered care therefore challenges the presumed loss of personhood that has tended to dominate the narrative on dementia: “It may sometimes be difficult to see the personhood in others who have advanced dementia but the assumption is made that it is always there to be found.” (Brooker & Latham, 2016, p. 18).

1.3 RESEARCH ON PERSON-CENTERED CARE

It is now recognized that people with dementia can achieve a good and meaningful life, despite institutionalization and the deteriorating nature of the disease, if they receive adequate support and good quality care (Edvardsson, Sandman, & Borell, 2014; Norwegian Ministry of Health and Care Services, 2015; WHO, 2017b). As a result, there have been increasing international calls for quality improvements in nursing homes (Brooker & Latham, 2016; McCormack et al., 2015; Røsvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011) and many governments have initiated reforms aimed at this (Fortinsky & Downs, 2014; Harding, Wait, & Scrutton, 2015). In Norway for instance, where over 80% of nursing home residents have dementia, research into services and care practices that reduce the consequences of dementia, meet the needs of persons with dementia and enhance quality of life have been advocated as a priority area (Norwegian Ministry of Health and Care Services, 2015). Both Norwegian dementia plans –

2015 and 2020 – highlight the need to implement a care approach that promotes the continued use of a person's abilities for as long as possible and works to maintain a person's identity and dignity despite the disease process (Norwegian Ministry of Health and Care Services, 2008; Norwegian Ministry of Health and Care Services, 2015). Person-centered care has been identified as such an approach (Ministry of Health and Care Services, 2015). For instance, WHO's Global Action Plan on the Public Health Response to Dementia for the years 2017 to 2025, states: "Integrated, evidence-based, person-centred care is required in all settings where people with dementia live, ranging from their homes, the community, assisted-living facilities and nursing homes to hospitals and hospices" (WHO, 2017b, p. 23). However, there is evidence from Norwegian studies that dementia care practice often boils down to attending to the basic necessities of the residents, and routine work continues to overshadow person-centered approaches (Heggestad, Nortvedt, & Slettebø, 2013, 2015; Malmedal, Ingebrigtsen, & Saveman, 2009).

1.3.1 Defining and conceptualizing person-centered care

Although PCC is widely recognized as the best way to practice dementia care, we still know very little about the current definition and implementation of this philosophy in dementia care settings (Epp, 2003). Translating concepts of PCC into practice remains challenging (Brooker, 2004; McCormack, 2004). As a result, several conceptual frameworks and models of practice, building on Kitwood's work, have been developed in an attempt to define, operationalize and facilitate person-centered care in practice (Brooker & Latham, 2016; Dewing, 2008; McCormack, 2003; Stranz & Sörensdotter, 2016). McCormack (2004) for instance, extracted four core concepts underpinning person-centered care; 1) Being in relation; 2) Being in a social world; 3) Being in place and; 4) Being with self. In other words, the relationships, the social environment, the context of care and the values and preferences of the person with dementia are all at the heart of person-centered care practice. Similarly, Brooker (2004) developed the VIPS definition, in which she identified four guiding principles of person-centered care: (V) valuing people with dementia; (I) treating people as individuals; (P) looking at the world from the perspective of the person with dementia and; (S) providing a supportive social environment. Brooker and Latham (2016) later developed what they called the VIPS framework, in which they operationalize person-centered care into achievable steps.

Dementia Care Mapping (DCM) is a practice tool developed by Kitwood and the Bradford Dementia Group to evaluate and improve the use of PCC in care units using observations and reflections. In Norway, Røsvik et al. (2011) developed and evaluated the VIPS Practice Model (VPM), aimed at facilitating caregiver use of person-centered care within the nursing home context. DCM and VPM have commonly been used in Norwegian studies and have been considered feasible tools to implement person-centered care (Rokstad et al., 2013; Rokstad & Vatne, 2011; Rokstad, Vatne, Engedal, & Selbæk, 2015; Røsvik et al., 2011).

1.3.2 Neuropsychiatric symptoms and person-centered care

A wide range of neuropsychiatric symptoms (NPS) is associated with dementia, especially in later stages of the disease (Jutkowitz et al., 2016). These include agitation/aggression, depression, apathy, psychosis and anxiety (Jutkowitz et al., 2016; Rokstad et al., 2013). These behaviours are distressing for the person with dementia and present a major challenge for caregivers and family members (Livingston et al., 2014; Malmedal, Hammervold, & Saveman, 2014). Studies have shown that a correlation exists between occurrence of neuropsychiatric symptoms and reduced quality of life (QoL) for persons with dementia (Mjørud, Kirkevold, Røsvik, Selbæk, & Engedal, 2014; Rokstad et al., 2013). Reduced QoL not only occurs as a direct result of the behaviour but is also due to inappropriate care strategies used to manage the challenging behaviours (Kitwood, 1997; Livingston et al., 2014; Malmedal et al., 2014). For instance, chemical restraints are often used to control NPS, although this mode of action is rarely recommended (Rokstad et al., 2013). Selbæk, Kirkevold, and Engedal (2008) found that long-term use of psychotropic medication in persons with dementia was common in Norwegian nursing homes, despite uncertainty about symptom improvement.

Conversely, PCC theory argues that NPS should be understood as strategies used by persons with dementia to communicate an unmet need. Therefore, in order to increase QoL for the person with dementia, caregivers should strive to resolve the underlying reason for the behaviour, rather than focusing on resolving the behaviour itself. Hence, some studies have attempted to highlight the association that exists between quality of care (QoC), QoL and NPS using a person- centered care approach (Chenoweth et al., 2009; Livingston et al., 2014; Rokstad et al., 2013). In Norway, Rokstad et al. (2013) studied the effect of two PCC frameworks – the VPM and DCM – on Quality of Life and Neuropsychiatric symptoms, concluding that PCC had positive effects on both QoL and depression.

1.3.3 Implementation issues

As mentioned above, several frameworks and methods have been developed to try to facilitate implementation of person-centered care in long-term care facilities. However, even in nursing homes that have introduced some form of PCC practice model, little is known about whether this PCC philosophy has actually led to a change in practice. As Edvardsson, Sandman, et al. (2014) suggest, there is a major gap in the literature with regard to post-intervention change in care competence and practice. The literature focusing on competence has mostly used the P-CAT (PCC assessment tool), which surveys change in staff self-perceived person-centeredness as a measure of change in PCC competence. In Norway for instance, a quantitative study by Rokstad et al. (2017) investigated whether the Dementia ABC educational programme (developed by the Norwegian National Advisory Unit on Aging and Health) could effectively increase staff competence in person-centered dementia care. After two years of educational training and a 6 months follow-up, findings revealed a positive change in participants' self-reported person-centeredness. However, it recognized that self-reported person-centeredness needs to be further explored using qualitative methods to investigate whether the self-reported competence in PCC actually translates into a change in practice.

Moreover, a review of the literature regarding PCC in various countries reveals major structural and organisational barriers to its implementation, including time constraints, staffing ratios and competing organizational demands (Harding et al., 2015; Innes, Macpherson, & McCabe, 2006; Moore et al., 2017; Smythe, Bentham, Jenkins, & Oyebode, 2015; WHO, 2012). Echoing these findings, Rosvik, Engedal, and Kirkevold (2014) argue that certain structural and psychosocial conditions need to be met for PCC at the dementia care unit-level to be successfully implemented within Norwegian nursing homes. These include smaller units, proximity between staff and leader and adequate staff-resident ratio.

A qualitative study by Talbot and Brewer (2016) focusing on care assistants' experiences with dementia care in the UK revealed that other factors, beyond organisational issues, were important in shaping the quality of care. For instance, person-centered care interactions were neglected even when adequate time was available for caregivers to spend with residents. In this study, a weak understanding of dementia and lack of staff training emerged as important barriers to effective dementia care. A similar study set in Ireland, exposed a substantial disparity between policy and practice in two nursing homes with a PCC policy (Colomer & de Vries, 2016). Again, care assistant knowledge and training in person-centered care was limited or absent and although some elements of the care approach were implicitly mentioned as aspects of good care, task-based approaches to care remained dominant. Although Talbot and Brewer (2016) and Colomer and de Vries (2016) also reported time and staffing constraints as barriers to person-centered care, these two qualitative studies challenge the assumption that organisational barriers are the only factors impeding on the delivery of person-centered care and highlight additional obstacles pertaining to knowledge and education that need to be addressed in order to improve service delivery. The present project seeks to further explore these findings within a Norwegian context using qualitative methods. Additionally, the two studies exposed what seemed to be inconsistencies between care assistants and managers' view of dementia care (Colomer & de Vries, 2016; Talbot & Brewer, 2016). Such a finding merits some attention and it would therefore be interesting in the present project to investigate dementia care both from the perspective of staff and management in order to further explore potential inconsistencies.

1.4 IMPLICATIONS FOR THE PRESENT STUDY

As Tom Kitwood predicted: "The challenge is to get organizations to do it [PCC], rather than simply maintain a façade" (Kitwood, 1997, p. 115). The overall issue surrounding PCC seems to be one of 'gaps': Gap between policy and practice; between theory and practice; and between what is said to be done and what is actually done. Hence, a wealth of literature in Norway and abroad has focused on developing, using or evaluating implementation frameworks to facilitate application of this elusive concept into practice. Still, little is known about the everyday institutional practice of PCC in Norwegian nursing homes and the factors that influence it.

Qualitative studies from Ireland and the UK have found variability in staff knowledge, understanding and use of PCC (Colomer & de Vries, 2016; Talbot & Brewer, 2016) revealing that issues beyond structural problems might contribute to the inconsistency in PCC practice. Could the scarcity in PCC implementation for persons with dementia be a knowledge problem?

As highlighted in this literature review, there is still a paucity of qualitative research regarding staff experiences with person-centered dementia care in Norway. We still lack insight into how staff perceive and understand person-centered care theory, and in cases where person-centered care competence is reported, we have yet to explore how this competence is translated and used in practice. Indeed, few studies have attempted to investigate staff understanding of person-centered care theory by, for instance, comparing specific descriptive accounts of staff-resident interactions with observations. The Norwegian dementia plan 2020 reported that even though professional training has become more widespread, a large proportion of dementia care personnel, especially temporary and part-time workers are highly likely to lack relevant training. As such, focusing on health personnel knowledge of person-centered care theory across levels of staff seems all the more important. The present study is validated by the recognition of a need to better understand what has largely been neglected until now – namely health personnel knowledge of care theory and the ways in which this knowledge may or may not translate into practice. It is the intention of this project to fill some of this gap by exploring knowledge of person-centered care within the Norwegian context. More specifically, this study aims to gain an in-depth understanding of the ways in which person-centered care theory and practice is understood, enacted or resisted across different levels of staff within the daily context of dementia care in Norwegian nursing homes. Taken together, the heterogeneous group of informants would be able to provide a unique insight into dementia care and the realities of person-centered care implementation.

CHAPTER TWO:
RESEARCH DESIGN AND METHODOLOGY

2.1 METHODS AND DATA COLLECTION

As mentioned in the literature review, many studies conducted in Norway have attempted to evaluate a range of implementation frameworks, the impact of person-centered care on staff and residents, and measure staff person-centeredness using quantitative approaches. Moen and Middelthon (2015) define qualitative research methods as "approaches that can be used to discover and examine they ways in which interconnected people encounter, perceive, understand and bring into being processes, practices and phenomena" (p. 322). Furthermore, Moen and Middelthon (2015) contend that this type of design can be useful when exploring patient-health worker relationships. Hence, the use of a qualitative design for this project is validated by the recognition that this method can provide us with additional knowledge related to dementia care research that has not yet been uncovered through structured quantitative approaches. This qualitative study is an attempt at addressing the current knowledge gap that exists within Norwegian literature regarding person-centered dementia care by providing a deeper exploration of the reality of person-centered care in practice. The objective of the study was to gain an in-depth understanding of the ways in which person-centered care theory and training is understood and utilized by nursing home managers and staff within the daily context of dementia care in Norwegian nursing homes. These objectives required an exploration of staff's perceptions of dementia, their experiences with person-centered care, their interpretation and understanding of this approach to care, and specific descriptions of how this knowledge is enacted, utilized and/or resisted on a daily basis within the nursing home. So as to best delve into these explorations and capture these processes, the study was inspired by an ethnographic approach described by Hammersley & Atkinson (2007) as:

> The researcher participating […] in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews […] – in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry (p. 3).

Moreover, utilizing both conversational and observational data collection methods produces different types of knowledge, all essential to the researcher's inquiry (Moen & Middelthon, 2015, p. 321). In depth-interviews allowed for the participants' narrated experiences of caring for- and interacting with nursing home residents to be fully explored, while observations provided me with an essential understanding of the context in which this care is shaped and enacted.

2.1.1 In-depth, semi-structured interviews

Because person-centered care is nationally recognized as an approach that should be implemented within all nursing homes, limited knowledge, inappropriate understanding or lack of implementation of person-centered care in practice could potentially be a difficult or sensitive topic for nursing home managers and staff to discuss. Thus, to realize the research objectives, it was of utmost importance that the interviews allowed the participants to openly share their experiences without feeling judged, and provided a safe space for them to open up about the different ways in which person-centered care is utilized or resisted on a daily basis. Furthermore, person-centered care theory is abstract and implementation into practice can be conceptualized in many different ways; using structured pre-determined interview guides would have limited the interpretation of person-centered care and would therefore have been inappropriate. Rather, the interview guide consisted of thematically-guided, open-ended questions that aimed to explore informants' theoretical and practical understanding of person-centered care without restricting their narratives. In addition, the interviews served to gain an insight into the challenges surrounding person-centered care implementation. As the various professional roles held by my informants served to illuminate different aspects of the same topic, I developed separate interview guides for nursing home managers and head nurses, and for nurses and care assistants (see appendix 1). In addition, I completed one interview with an activity coordinator in one of the nursing homes. In total, I carried out 13 individual interviews that lasted between 30 minutes and 1 hour 45 minutes. All interviews were tape recorded, and transcribed verbatim as the fieldwork progressed.

In the early stages of fieldwork, I was aware that other conversational data collection methods such as focus group interviews, could be an option to explore, but after careful consideration I decided against it. My decision was motivated by several factors. Firstly, although focus groups have been praised for their practicality, both in terms of larger sample sizes and time/cost-effectiveness (Liamputtong, 2011), the reality is that bringing together a group of people can often prove to be an arduous task (Kielmann, Cataldo, & Seeley, 2012, p. 38). This is especially relevant to the context in which my fieldwork took place. Due to the hectic nature of their work schedules and the limited number of staff on shift at one time, gathering enough people for a focus group would have been hard to achieve. Secondly, my main intention was an in-depth exploration of individual theoretical and practical understanding of person-centered care. Although focus groups have the potential to reveal a wide range of views and understandings (Brinkmann & Kvale, 2015, pp. 175-176; Liamputtong, 2011, pp. 3-6), a group environment would not have been appropriate in conveying the type of detailed knowledge I was seeking, and merely run the risk of presenting the views of a few outspoken participants (Grbich, 1999, pp. 109-114; Liamputtong, 2011, p. 8). Thus, I regard the combined use of in-depths interviews and observations, to be an appropriate strategy that would allow me to capture some of the advantages brought forth by the use of focus groups.

2.1.2 Observations

Glesne (2006) describes participant observation as a method through which the researcher strives to gain a deep understanding of the research setting and the participants by becoming a part of the context in which the study is unfolding (pp. 49-52). My reason for using observation was two-fold; firstly, it was guided by the desire to gain insight into the daily context of dementia care. As a Masters student with a background in global health and psychology, the field of dementia, and particularly dementia care, was somewhat unfamiliar to me. Thus, it seemed imperative to familiarize myself with the field through the lens of those most closely involved with dementia care. Although I had delved into countless books and research studies on person-centered care, observations improved and supplemented my understanding of the field and more generally the field of dementia care in ways reading literature or even interviewing could not. I recorded as much as possible, aiming my attention at all aspects of the study environment that seemed relevant; the social environment, encompassing routines, tasks, staff dynamics, staff-resident relationality, language, care practices, events and activities. But also, the physical environment, including the wards layout, the furniture used, the rooms, the smell, the noises.

Secondly, use of participant observation was motivated by the nature of my research inquiry. When used alongside interviews, observation serves to explore the congruence between the participants' actions and narratives (Glesne, 2006, p. 49). This seemed especially relevant to the present study, as it attempted to explore how nursing home staff understood person-centered care and how this knowledge was enacted or resisted in practice. Hence, my observations, combined with the interviews I conducted, were used to gain an insight into potential discrepancies between what was said and what was done. Moreover, the use of participant observation allows the researcher to establish a relation of trust with his/her informants (Glesne, 2006, p. 49; Hammersley & Atkinson, 2007, pp. 63-96). Similarly, spending as much time as possible in the ward was instrumental in gaining the trust of those who would become my interview participants.

As Glesne (2006, pp. 49-50) describes, researchers engaging in observation may find themselves taking on different roles throughout the data collection process, fluctuating between states of pure observation to full participation, depending on the nature of the research question and the context in which the research is taking place. Throughout my fieldwork, I found myself taking on different roles along this participant-observation continuum, constantly oscillating somewhere in between "observer as participant" and "participant as observer". In the beginning, I assumed a role closely resembling that of "observer as participant", described as the phenomenon by which the researcher positions himself/herself primarily as an observer, but has some interactions with the informants (Glesne, 2006, pp. 49-50). I was wearing their uniform, showing up for shifts, engaging in informal conversations during morning meetings or in the staff lounge. As I slowly became a natural part of their work environment, I found my role changing. Increasingly interacting with staff, I took part in events and internal training seminars and I assisted in meal preparations and other practical chores. Through my participation in daily routines I also had informal interactions with residents, in the form of serving coffee or meals, sitting around the living room and participating in organized activities. Switching between different roles, allowed me to shed light on different aspects of my research inquiry. I could for instance take a step back, exploring dementia care practices through the observation of staff-resident interactions, but also, to some extent, gain an insider understanding of the workplace culture and the overall context in which these care practices were shaped. My field notes were recorded in a notebook and later transcribed onto a computer for analysis.

2.2 SAMPLING, SAMPLE SIZE AND RECRUITMENT

2.2.1 Sampling and recruitment

Gaining access to nursing homes proved to be more difficult than expected. My aim was to be able to access two nursing homes. This number was chosen in accordance with the fieldwork's timeframe (September – December 2017), the research inquiry and the research design. It was my intent to spend a significant amount of time (about five to six weeks) within each institution in order to extract rich contextual data. It was therefore realistic to consider that two nursing homes would be suitable to explore the research topics within the set timeframe. The initial strategy used to gain access to nursing homes was through snowball sampling (Silverman, 2013, p. 203). My co-supervisor, who is a researcher at the Norwegian National Advisory Unit on Ageing and Health, was an important point of contact. Based on her suggestion, I contacted several nursing homes in the Oslo-area that were known to have previously participated in projects regarding person-centered care. In the end, I was able to meet with a nursing home manager, and after several planning meetings with her and other staff members, I was given consent to start my fieldwork at their institution. The aforementioned manager also played a central role in facilitating access to the second institution by putting me in contact with a former colleague of hers, who was a head nurse at this facility. Although I was able to start fieldwork fairly quickly at the first institution, difficulties arose when trying to find a convenient time to begin the second part of my fieldwork. As a result, I spent a significant amount of time at the first facility (from September to November 2017) while awaiting the go-ahead from the other nursing home. I was there for a month, between November and December 2017.

Once I gained access to the study sites, the process for recruiting interview participants was more purposeful. Because this study aimed to explore caregiver knowledge, understanding and enactment of person-centered care across levels of staff, maximum variation within the sample population was required. Additionally, the selection of a heterogeneous sample of informants was motivated by the desire to gain a better understanding of the organisational culture within which the study was taking place. Hence, informants were selected using purposive sampling (Silverman, 2013, pp. 148-152) to include health personnel with different educational background and level of training. The process was slow at first, as I decided to dedicate the early days of fieldwork (or as Hammersley and Atkinson (2007) call it, “field negotiations”) to getting to know the people and the place that made up the research setting. Indeed, Hammersley & Atkinson (2007) write that “the value of pure sociability should not be underestimated as a means of building trust” (p. 70). Taking the time to establish a good relationship with staff was essential, as I wanted to make sure they understood my purpose for being there and would feel comfortable having me around (Glesne, 2006, pp. 52-53; Hammersley & Atkinson, 2007, pp. 63-96). Moreover, establishing a good relationship with the people who had welcomed me into their space, laid the foundations for recruiting participants for the interviews. Informants included temporary/part-time staff, care assistants, nurses, head nurses, an activities coordinator and a nursing home manager. Despite differences in professional roles, all participants had extensive experience working in dementia care, with years of experience ranging between 8 to almost 40 years. Most of the interview participants were women, with the exception of two men. The overrepresentation of women in the sample was not intentional, but rather a reflection of the fact that women constitute the main workforce in occupations associated with nursing and caregiving.

2.2.2 Sample size

Prior to beginning my fieldwork, a tentative sample size had been set to 15-20 informants across two nursing homes, preferably 10 from each institution. Once in the field, this goal no longer seemed realistic. Firstly, I ended up spending significantly less time at the second institution than previously anticipated. As a result, I interviewed nine people at the first nursing home, and four at the second. Moreover, the hectic nature of their work environment often made it difficult for participants to find a convenient time to take part in the interviews. Moving beyond logistical reasons, limiting the number of participants was also a conscious decision. Due to the nature of the study design ('mini-ethnographic' approach combining observations and interviews), I felt it was important to spend a significant amount of time getting to know the people in my study, prior to beginning interviews (Hammersley & Atkinson, 2007, pp. 63-96). Additionally, as time went by, the interviews seemed to reach a point of saturation, with little new knowledge to be extracted. Most importantly, the depth and length of the interviews required me to limit the number of informants so to have time to thoroughly analyse the content of the interviews (Brinkmann & Kvale, 2015, pp. 140-142).

2.3 DATA ANALYSIS

Hammersley and Atkinson (2007) contend that analysis of data is not an isolated step of research, but rather integrated throughout the entire process of any ethnographic research (pp. 158-190). I would argue that in my case, a process of analytical reflection was present while jotting down notes in my notebook and expanding on those notes following a day in 'the field'. Analysis was certainly also shaped throughout other stages of my fieldwork – during literature review, interviews, observations in different study sites and transcription. The way one approaches the data collected is also largely guided by the research problem itself, and therefore no single procedure or protocol should be blindly followed when engaging in data analysis (Hammersley & Atkinson, 2007, pp. 158-190). My approach to the transcribed interviews and the field notes can be described as consisting of a number of interconnected steps, based on core principles of qualitative or ethnographic thematic data analysis. Firstly, the analysis process began by what Moen and Middelthon (2015) refer to as "developing an intimate acquaintance with the data" (p. 356), not only through my presence in the field, but also through more concrete actions such as listening to, and transcribing interviews, typing up field notes and rereading the material while jotting down additional thoughts or ideas (Hammersley & Atkinson, 2007, pp. 158-190; Moen & Middelthon, 2015, pp. 355-360). What followed was making use of a computer analysis program (Nvivo), to reorganize my data through the generation of codes and concepts (Hammersley & Atkinson, 2007, pp. 158-190). The data material was organized and analysed in a range of ways. For instance, organizing the material according to thematically-related codes, while considering the potential patterns that could emerge from participants sharing the same professional roles or working within the same setting (Hammersley & Atkinson, 2007, pp. 158-190; Moen & Middelthon, 2015, pp. 355-373).

As the essence of my research problem concerned the understanding and use of person-centered care theory, this was of course a theoretical paradigm that informed my analytical process. However, reducing the data I had collected to simple descriptive codes of staff's practical or theoretical understandings of person-centered care seemed hardly appropriate. Hence, while the knowledge of Kitwood's (1997) theoretical and practical approach to dementia care served to generate themes, I remained open to the spontaneous emergence of non-previously identified themes from the data material. Hence, the process of generating codes and themes was characterised by both deductive and inductive approaches (Hammersley & Atkinson, 2007, pp. 158-190), leading me to discover themes that surpassed the individual realm, to include interpersonal, organisational and national influences on enactment of person-centered care. After a continuous process of coding, recoding, focused coding and rearrangement of codes, central themes and sub-themes were identified and further analysed to clarify how they related to each other and their context. For instance, a process of comparison was undertaken as I looked for patterns and nuances within themes (Hammersley & Atkinson, 2007, pp. 158-190; Moen & Middelthon, 2015, pp. 355-373). Were there any nuances between the data collected from interviews and the data collected from my own observations? Were there any differences between people with caregiver roles and those in administrative positions? Themes were also further reflected upon through the use of visual charts in Nvivo, and consultation of the literature in the areas of care, nursing, and organizational culture and management. The various thematic codes that emerged were classified into two main groups: (1) The meaning of person-centered care; (2) The implementation of person-centered care.

2.4 ESTABLISHING TRUSTWORTHINESS

Throughout the chapter I have touched upon some of the procedures of this study, that can help establish ‘validity’, or *trustworthiness*. For instance, engaging in triangulation and providing a detailed description of my data collection and analysis process, are strategies that can be used for this purpose (Malterud, 2001; Nowell, Norris, White, & Moules, 2017). In addition, trustworthiness can be demonstrated through a thorough account of the process of *reflexivity* and *transferability* (Malterud, 2001; Maxwell, 2012, pp. 121-138; Nowell et al., 2017), which will be discussed in this section.

2.4.1 Reflexivity

According to Malterud (2001), *reflexivity* is an important factor to consider when setting out on a qualitative inquiry if we are to maintain scientific rigour throughout the research process. Hammersley and Atkinson (2007) describe reflexivity as a process “that acknowledges that the orientations of researchers will be shaped by their socio-historical locations, including the values and interests that these locations confer upon them” (p. 15). Reflexivity therefore entails an ability to address any potential preconceptions or beliefs that the researcher might have, that could shape the investigation. Using reflexivity thus serves to maintain trustworthiness, by accounting for any effect the researcher might have on the research material, and by helping the researcher distinguish between knowledge formed from preconceptions and new knowledge emerging from the research inquiry (Malterud, 2001). In line with Malterud’s discussion on reflexivity, and acknowledging that there is no such thing as a ‘neutral observer’, I provide below some reflections on my own motivations for pursuing the research project. Here, I strive to address how my position as researcher shaped my choices of fieldwork and methods, and the thematic analysis that ensued.

Firstly, it was important for me to recognize that previous – and rather gloomy – personal experiences from nursing homes in Norway and Canada had been decisive in shaping my determination to explore this particular field. As such, I was aware that pre-study beliefs and expectations regarding low standards in dementia care needed to be addressed and thoroughly reflected upon throughout the research process to avoid any risk of introducing bias. In light of this, I approached fieldwork with an open-mind, using my field notes as a platform for personal reflection.

Secondly, despite having accumulated theoretical knowledge on the issue, I am not a nurse, nor a professional caregiver, and I have no professional experience when it comes to working in eldercare. I believe that this level of unfamiliarity with the field of dementia care positioned me as a 'novice learner', making it somewhat easier for me to take a step back and capture processes that may have been disregarded as 'commonsensical' by someone already affiliated with the field. Moreover, I have no doubt that my lack of training in nursing and eldercare not only shaped the way I approached my study setting but also how I was received by those I intended to study. In the early days of fieldwork, I could not help but feel a certain level of inadequacy when questioned about my credentials. But making my intentions clear and positioning myself as a novice researcher eager to learn, rather than an expert scrutinizing their behaviour, might have actually facilitated my rapport with participants. Similarly, Hammersley and Atkinson (2007) contend that: "the researcher's appearance can be an important factor in shaping relationships with people in the field" (p. 66). In light of this, I am aware that choosing to follow the dress code of the institutions may have shaped how I was received and the type of data elicited.

Finally, I am aware that data interpretation undoubtedly varies according to the theoretical perspectives that the researcher chooses to engage with during analysis (Malterud, 2001). Furthermore, the techniques chosen by the researcher will depend on "the content and purpose of his or her inquiry" (Brinkmann & Kvale, 2015, p. 223), and the theoretical approach will to some extent be dictated by the researcher's particular field or discipline (Hammersley & Atkinson, 2007, pp. 1-19). With a background in global health and psychology, I have not been trained into a specific discipline. I am not an anthropologist, nor a health care professional. I was therefore motivated to engage with a diverse range of disciplines, concepts, theories and authors to inform my choice of methods during the data collection and analysis process, to frame and present my arguments, and to inspire my form of writing.

2.4.2 Transferability

Another important question to consider when designing and carrying out a qualitative research study relates to the issue of *transferability*, namely: to what degree are the findings of the present study applicable to other settings? Firstly, it is important to note that "no study, irrespective of the method used, can provide findings that are universally transferable." (Malterud, 2001, p. 485). It is essential however, to take a moment to consider the nature of the findings, and in what other context or setting, if any, the findings that emerged from my data analysis could be relevant (Malterud, 2001).

Some may argue that the ‘subjective nature’ of the qualitative inquiry, the sample size and the specific setting of this study pose limitations to the transferability of findings to other settings. There is no denying that some aspects of the material I have collected are restricted to the two institutions in which fieldwork was carried out, and as such, could not be applicable beyond the study setting. Certainly, some of the experiences and perspectives of the individuals in this study, for instance concerning specific challenges with residents, colleagues or the organisation of work tasks, represent unique responses to the specific context in which they work, and may therefore not be readily transferable to other settings. However, similarities in findings between the two institutions I studied, and the existing parallels between the present findings and findings from studies abroad, suggest that circumstances related to the broader social and organisational aspects of person-centered care understanding and implementation are not isolated instances, but rather shared by many nursing homes. Hence, it could be argued that the overall findings related to staff understanding of person-centered care and the perceived issues regarding its implementation, as reported in this study, can give valuable insight to others working within dementia care in Norway, certainly, and perhaps even in similar settings abroad.

2.5 ETHICAL CONSIDERATIONS

According to the Belmont Report (1978), defining traits for vulnerability include dependency and inability to consent. In the case of persons with dementia, the gradual loss of cognitive abilities, would be considered a condition that diminishes a person’s capacity to consent (Higgins, 2013; Pierce, 2010) thereby defining this group as “vulnerable” and in need of increased protection. Similarly, the *International Ethical Guidelines for Biomedical Research Involving Human Subjects* developed by the CIOMS recognizes that elderly persons are commonly defined as a vulnerable group, especially if institutionalized and/or suffering from dementia (CIOMS, 2002, guideline 13). The current situation and the alarming projections for the future undeniably call for the advancement of scientific knowledge on dementia as a major interest of society. On the other hand, the very nature of the disease poses practical and ethical challenges that make it extremely difficult to obtain ethical approval for studies involving persons with dementia (Holland & Kydd, 2015). Taking this into consideration, I decided not to focus my project on persons with dementia, but rather on the experiences of health personnel as related to dementia care. To avoid any potential issues, a Remit Assessment form was sent to the Norwegian Regional Committees for Medical and Health Research Ethics (REK). The project was deemed to fall outside the scope of REK and given clearance. A notification form was also sent to the Norwegian Center for research Data (NSD) and approved (See appendix 3). Nevertheless, I am aware that my research inquiry involved observation and that my presence within the nursing home would undeniably pose a potential for a limited amount of interaction with residents. However, out of ethical considerations, at no point did I discuss the project, nor ask questions related to the project with persons who were not participants. Additionally, observations were meant to solely give an in-depth understanding of care from the perspective of the health personnel. I believe that by being constantly aware of this aspect, and actively focusing my attention on the work of my informants rather than the residents, I was able to avoid any potential harm. Additionally, my role and the purpose of the project were clarified during several planning meetings with staff, and I was given consent by both nursing homes before starting fieldwork. With regards to the interviewed informants, consent forms were used in order to clarify all of the important aspects of the research inquiry, and no persons were involved unless written consent had been obtained (see appendix 2). To ensure confidentiality, any information that might have been used to identify informants - including name, location of fieldwork, and/or any other descriptive features that could be linked back to the participants - were changed or omitted. For instance, participants were disidentified by the use of age, gender and occupation instead of names. Field notes were also disidentified in this way and kept safe under lock. Audio recordings were stored safely on a password-protected UIO server and deleted from the recorder. Moreover, any recognizable reference to names of places or people, were omitted during interview transcription.

CHAPTER THREE:

THE MEANING OF PERSON-CENTERED CARE

- FROM THEORY UNDERSTANDING TO INDIVIDUAL PRACTICE -

> "It's really just basic common sense… that one should behave properly towards another human being. That's what it's all about… really that entire care philosophy is about behaving properly"
>
> Sonja[2], nurse

> I am following Gabriel around the ward. In the little time that I've gotten to know him, I've noticed that he seems to bring in a very special type of energy to the ward. His smile, his laugh and his upbeat personality seem to be the hallmark of this care assistant. The morning meeting just ended, and it's time to get residents ready for the day. I watched as he prepared to walk into a resident room. A gentle knock, then a pause. The resident is already up and Gabriel walks in and greets her. How is she doing today? Did she sleep well? He's lively, smiling, engaging in conversation. He helps her into the bathroom, where she is able to do a lot of the morning care on her own. He doesn't take over, he facilitates, he guides. What does she want to wear today? He walks to the closet and picks out a few shirts and bras. He doesn't take over, he lets her choose. The conversation is cheery, they're laughing together. It's a friendly interaction and I instantly recognize how this moment reflects features of person-centered care. I discern Kitwood's 'Recognition', 'Collaboration', 'Negotiation' and even 'Celebration'. Later that morning I reconvene with him and attempt to approach the topic of person-centered care. I was curious to know more about how he perceived this approach, how he understood it. That's when he tells me that he hasn't really heard much about it.
>
> (Excerpt from field notes, Peaceful Gardens, Sept. 2017)

The excerpt above was chosen because I believe it reflects an important starting point for the following discussion. Specifically, it encapsulates what some of the literature on the implementation of person-centered care has, and continues to grapple with: firstly, it's a demonstration that whilst national and institutional policies and guidelines may very well encourage and front a person-centered care approach, the people directly in charge of delivering this care are often unaware of what it means and what it entails (Kitwood, 1997; McCormack et al., 2015). Secondly, it suggests that principles of person-centered care may be intuitively present in professional caregivers, even in the absence of PCC-specific training (Colomer & de Vries, 2016; Helleberg & Hauge, 2014; Talbot & Brewer, 2016). Thirdly, it brings focus to whether proper implementation of person-centered care in practice (or lack thereof) is determined by organizational resources, or rather a product of the attitude, beliefs and values

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[2] All names used throughout the thesis are fictitious

held by caregivers (McCormack, 2004; Moore et al., 2017; Talbot & Brewer, 2016). The following chapter delves into the first two issues, namely the knowledge and the meaning of person-centered care. I will return to implementation of person-centered care at the institutional level in a later chapter, but for now the issues relating to person-centered care understanding bring forth important questions: How was this care theory defined and understood by the people I interviewed? How was their individual conception of person-centered care theory translated into daily practice?

In a qualitative meta-synthesis exploring ‘person-centeredness’, McCormack, Karlsson, Dewing, and Lerdal (2010) argue that research into this field has flourished into a “silo mentality” (p. 621), lacking integration of new knowledge, shared meaning and clarity concerning the concept of ‘person-centeredness’. According to the authors, we are increasingly witnessing “the development of multiple and sometimes competing understandings of person-centeredness and the desire to find concepts that go beyond person-centeredness” (p. 621). I do not disagree with McCormack et al. (2010) on this point. I myself have found a great level of difficulty navigating the ever-increasing literature on ‘person-centeredness’, ‘person-centered care’, ‘patient-centered care’, ‘relationship-centered care’ and the innumerable concepts and frameworks that have derived from these theories. It almost seems as if the initial attempt to clarify and concretize Kitwood’s (1997) theoretical principles of person-centered care, has now developed into fragmented knowledge that is failing to achieve consensus on terminology and meaning. With the lack of a common framework, care model, or working definition, it is not surprising that the meaning of person-centered care, and how to ultimately achieve it, has remained elusive to many working within dementia care.

Indisputably, the analysis of my data material confirms this elusiveness. However, despite the participants’ diversity in knowledge and definition of person-centered care, their understanding of person-centered care emerged as encompassing three common (and naturally overlapping) themes: *Seeing the person (‘å se’)*; *Knowing the person (‘å kjenne’/‘bli kjent med’)* and; *Empowering the person (‘oppleve mestring’).* Furthermore, staff engaged in various strategies, or processes, to translate their understanding of person-centered care into practice. These processes, which were inextricably linked to their understanding, emerged as several subthemes from my data material: *Reframing dementia; Humanizing and depathologizing behaviour; Taking the person’s perspective; Life stories; Relationality; Not taking over* and; *Being in the now.*

3.1 ON SEEING THE PERSON, Not the Disease

> "The person is in front, the disease is behind! But today we see the condition before the person, and we forget the face… and there's a lot of people who say: 'they are demented, they don't understand'…"
>
> Mona, care assistant

In the following section I will explore the theme that I have chosen to call *'seeing the person'*. The term 'seeing' is used symbolically here, to represent not only the mere act of seeing, or "to perceive by the eye" (Merriam-Webster, 2018)[3], but rather involves *seeing* as a process of reflection, recognition and humanization on the part of the caregiver. As will be presented and discussed, seeing the person was an important theme throughout the interviews, as staff described person-centered care as the ability to see the person holistically, paying attention to their individuality, their needs, their interests, and their environment. Seeing the person involved several processes: *Reframing the dementia condition; depathologizing behaviour* and; *taking the resident's perspective*.

Throughout his work, Kitwood criticized the medicalization of dementia and what he took as a dominant focus on neuropathological processes, which in his view merely served to erase the person behind the condition. In his opinion, this way of conceptualizing dementia, which he termed 'the standard paradigm', was too narrow and deterministic (1997, p. 37). Instead it was proposed that the ways in which dementia is expressed, and its progression, is shaped not only by neuropathology but also by broader psychosocial conditions (Innes, 2009, pp. 1-26; Kitwood, 1997). This position has now been widely accepted, as proven by the increasing amount of literature regarding person-centered care. According to Kitwood (1997), the way we approach care is inextricably shaped by how we view dementia. Similarly, Castillo (2011) recognizes that "the first step to treating patients with dementia differently is to begin to recognize how cultural notions of personhood, of what makes a person a person, shape the meaning and experience of dementia" (p. 274). A good point of departure then, is to inquire into how the dementia condition and the person with dementia was perceived and understood by the different staff members. It was clear from the interviews that the majority of staff, regardless of their professional role, emphasized the need to see the person before the disease. As one care assistant at *Bay Views* expressed when talking about person-centered care:

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[3] "See." Retrieved from https://www.merriam-webster.com/dictionary/see

> *It's about thinking that it's a person who has dementia, and not dementia who has a person umm... think of it as a person with dementia and not dementia with a person, in a way. By saying 'dementia with a person', I mean that we're focusing only on the pathological aspects... that becomes the focus... the medical (aspects) and everything... but instead we must think that this is a person with a condition.*

This is reminiscent of how Kitwood (1997) attempted to rethink the dementia paradigm, from "person-with-DEMENTIA" to "PERSON-with-dementia" (p. 7). Indeed, *reframing dementia* to in order to bring the focus to the person rather than the disease, was perceived as important by several staff members. For instance, some carers emphasized the role of the psycho-social environment when talking about dementia, such as one care assistant from *Peaceful Gardens* related when asked to define the condition:

> *[Long pause] it depends on the perspective you're taking... you know, like I said, when I started 8 years ago, dementia for me was a completely different world, and at that time in my homeland, there was no focus on it. And when I started here I thought, now I need to read more about it, and I got the opportunity to work with environmental therapy, and then I started thinking, yes actually, environment can affect how dementia progresses. But the environment doesn't decide if I or you will get dementia, so then biology and the actual disease comes into play... so now, after getting support from work to take 1 year of environmental therapy for persons with dementia, I got more knowledge. I got another perspective... through theory and lots of other things... so umm, both. Dementia is not... I don't like saying "that person has dementia" [points] because that person has a name. You understand?... yes, dementia is a disease, biologically, physically, physiologically, yes. But the environment is significant too!*

Accounts such as this one, which minimize the dominant medical aspects of dementia, illuminates two significant points; firstly, it reshaped how certain carers understood the caring context, and in doing so, allowed residents to be defined not by their diagnostic label, but by other more relevant attributes that maintained their identity. In this sense, personhood was not obscured by the disease, but upheld through the *reframing of the dementia condition*. By capturing the broader psycho-social context of dementia, most participants showed an understanding of the fundamental underpinnings of person-centered care, namely that the "story of one's person's dementia is much more than that of an advancing neurological illness" (Kitwood, 1997, p. 41).

Secondly, *reframing dementia*, and subsequently the person with dementia, also seemed to inform how staff interpreted the residents' behaviours. Rather than viewing 'challenging' behaviours among residents as a disease marker, most staff members, regardless of their professional roles, interpreted these behaviours as the person's method of communication or response to the current environment. In other words, they attributed meaning to the behaviours.

This is in accordance with the call for depathologizing behaviour, raised by person-centered care, whereby one should strive to interpret behaviours from the perspective of the person with dementia, rather than marking behaviours as disease symptoms to be 'eliminated' through pharmacological interventions (Brooker & Latham, 2016; Edvardsson, Winblad, & Sandman, 2008; Kitwood, 1997). For many informants, interpreting residents' behaviours as carrying a communicative function was important in guiding their care strategies. Rather than turning to the use of sedatives to eliminate 'challenging' behaviours, staff focused on attempting to understand how their actions, the environment and the quality of staff-resident interactions could worsen or alleviate the resident's behaviour. As one administrator stressed:

> *I want them to use 'miljøbehandling' ('environmental therapy') first. And so that 'kartlegging' ('mapping') that is done in advance is very important. Because I… I don't think using medication always works. Especially for persons with a dementia diagnosis… because they would react differently to medication than others. Human contact, see and be seen, and be heard… maybe using redirection to take them out of a situation… use oneself much more.*

Here, *seeing the person*, is described as inevitable if one is to engage in non-pharmacological behavioural interventions. *Seeing the person* in a broader context and extracting meaning from their behaviour is exemplified in the following comment by a nurse at *Peaceful Gardens*:

> *Well I think it's natural that some residents display challenging behaviours. I think we all would, if we were in that kind of situation. A situation where you don't really understand what is going on, and then someone comes along and acts in a way that seems very annoying [laughs], like someone may just start pulling down your pants... right? It's fairly… annoying that people (staff) do that. So naturally… I think anyone would get agitated or aggressive if someone acts the same way we do… right? And I mean… those residents who might perceive themselves as living in the past or in another reality, may not comprehend that their pants are stained with urine or faeces. So they might not see any reason to do something about it… so yes, it's only natural. It's only human to react that way. If you think about children sitting in a sandbox, hitting themselves with a shovel, is that challenging behaviour? Are those children acting out? [laughs]*

The nurse's statement "it's only human to react that way", reflects a process of *depathologization and humanization of 'challenging' behaviour* on the part of the caregiver, whereby the person with dementia is seen, and the behaviours are respected and understood. This process of humanization and personally identifying with the residents was echoed by many participants, as one care assistant similarly commented: "They are just like us…they have different personalities so then… they also react differently". As such, it seemed that for some participants, *seeing the person* rather than the disease, was brought forth by emphasizing the similarities that existed between the carer and the resident and identifying with the *residents' perspective*, minimizing the 'us-them' divide between caregivers and care recipients (Doyle & Rubinstein, 2013; Kitwood, 1997). In a qualitative study exploring embodied expressions of personhood, Kontos (2007) found that recognizing personhood involved health practitioners' use of imagination, which enabled them to identify with the existence of the care recipient, bridging "the gap between the care provider and the care recipient" (p. 563). This process of identification was echoed by several staff members in the present study, as exemplified by these following comments:

> *And the most important thing, I think, is that they are seen. We have to see them every day… we can't just walk past, we have to really see each and every one of them. And see how their situation is, and how their personalities are […] Maybe we should think about how we, ourselves, would like to be met when we end up in a nursing home. Maybe think about that when we walk into a resident's room... 'how would I want to be met?'… but that has a lot do with how we are as persons.*
>
> *If someone really enjoys staying in bed and they are 90 years old and frail, then I think, what would I want? That's why I say sometimes "when I'm old, let me just stay in bed with my laptop [laughs] and be on Facebook!" [laughs] yes maybe that gives me joy so yes […] good care is about knowing what the resident likes and maybe that has changed? So we just have to respect that, and try to hear them and see them*
>
> *If I think about myself, good care… for me, first and foremost it's about the patients. What do they feel? Are they safe? Do they feel loved? How is the environment? Are they heard? Are they seen? All these things that show when you look at a patient's face. You have to meet that. You have to be welcoming, smile and be happy, have an open face. Then you see that "yes, I've done a good job today"*

Seeing the person by *taking the resident's perspective* was perceived by staff as necessary in order to understand not only the behaviours, but also the needs and preferences of the residents. This process was beautifully captioned by an activities coordinator:

> *You have to just... see the individual, see their resources and... include them in things [...] not do things over their head... but take the time to see... if you're sitting around a table, at breakfast for example, take the time to see… what's going on around that table? Is "Fru Hansen" eating? Is she eating or is she not eating? Don't come and try to help her eat right away but... take the time to consider… that's important. Take the time to sit down and... talk to them, and... […] yes… really take the time to see, see the resident and where they are at... is she walking back and forth? Why is she walking?... should we put on some nice music, instead of having the TV on, that nobody is watching anyways? Maybe it's a good idea to turn off the CD-player if the TV is on? Or the other way around, not have both of them on at the same time… that happens too! […] but really, how would you want it at home? Think that… how would I want it at home?*

Through *seeing*, residents were not simply reduced to being "carriers of an organic brain disease" (Kitwood, 1997, p. 7) but recognized as unique persons, with intrinsic values, interests and needs. Edvardsson et al. (2008) remind us that person-centered care involves the ability to "regard personhood as increasingly concealed [by the disease] rather than lost" (p. 363). However, it seemed that *seeing the person* and recognizing personhood as "increasingly concealed rather than lost" (Edvardsson et al., 2008, p. 363) was sometimes difficult for some care assistants, especially as the disease progressed. Doyle and Rubinstein (2013)'s work on the cultural matrix of 'othering', may shed some light on this issue. They argue that enactment of person-centered care and recognition of personhood, can be obstructed by a process of othering, creating "an 'us vs. them' paradox" (p. 961). According to the authors, the process of othering is promoted through several mechanisms, including emphasizing the dementia status, focusing on functional dependence and making assumptions regarding challenging behaviour. For instance, they found that "the more similarities a resident had to the person interpreting their behaviour, the less the interpreter relied on the diagnosis of dementia to explain the behaviour" (Doyle & Rubinstein, 2013, p. 958). These ideas put forth by Doyle and Rubinstein (2013) seemed to materialize in the present study, as exemplified by one care assistant working at *Bay Views*:

> *When they become very different and difficult, that's when I think about the disease… yes, when they become difficult I only think about the disease, and so I have to try to… act in terms of the person as well, but I think about the disease.*

Here, the care assistant recognized that he emphasized the role of the disease as the residents became increasingly "different and difficult", an approach that was not uncommon among a few of the people I interviewed. The "us vs. them" divide described by Doyle and Rubinstein (2013) is apparent here. This is not to say that participants in the present study were engaging in a process of 'othering'. However, it can be theorized that *seeing the person* became more difficult to achieve as the disease inevitably obscured potential similarities between caregiver and care recipient. Similarly to some of the findings from Doyle and Rubinstein (2013), Castillo (2011) work on the anthropology of dementia and personhood reveals that cultural notions of personhood are often tied with the ability to be autonomous and independent (pp. 276-277). Thus, as dementia progresses and interdependence increases, it can be difficult to emphasize the continuing existence of the 'person'. Although Castillo's analysis was focused on American models of personhood, her findings seem comparable to the context of the care wards in this study, as exemplified by this care assistant's response when asked if he thought he could make a difference in residents' quality of life: "Yes… maybe for some… but not everyone… when you don't have control over your own body and you are dependent on everything… is that a life?"

This statement not only emphasizes the importance given to functional dependence, but it also illustrates how cultural beliefs of dementia as a "death that leaves the body behind" (Kitwood, 1997, p. 3) is still very much present, even among care professionals. Kontos (2007) contends that presuming loss of selfhood in advanced stages of dementia is not uncommon among caregivers. Likewise, Brooker and Latham (2016) write that "there is a high level of risk that people living with dementia are treated as if they are 'non-persons'. The risk of this is greater when the level of impairment is more advanced" (p. 18). The "unwavering commitment to the person to the last" (Davis, 2004, p. 376) as advanced by Kitwood, seemed to fall short here.

As reflected in this first section, *seeing the person* was achieved through several strategies, including *reframing the dementia condition*, *humanizing and depathologizing behaviour* and *taking the perspective of the person with dementia*. Although the discourse employed by staff was fluctuating between processes of humanization and depersonalization, depending on the 'severity' of the disease, it seemed that they all emphasized the significance of seeing the person, which was recognized as an important aspect of person-centered care. However, recognizing personhood, and understanding person-centered care, was not only captured through *seeing*. *Knowing the person* was another common theme throughout the interviews and regarded by staff as a fundamental tenet of person-centered care. This theme will be discussed in the following section.

3.2 ON KNOWING THE PERSON

> "We have to go through different things, from objects of value they are bringing with them, to their background, to have something to talk to them about, and get to know them and… in order to offer them the best care we have to know… get better acquainted with them. Because to us, they're like a blank page when they first move in."
>
> Ingrid, nurse

In the VIPS framework developed by Brooker and Latham (2016), treating people as individuals with "a unique history, identity, personality and physical, psychological, social and economic resources" (p. 12) is identified as an essential element of person-centered care, and this requires that nursing home staff should know about and act upon a person's uniqueness. Similarly, all staff members I interviewed recognized *knowing the person* as an essential part of person-centered care. In their view, *knowing the person* was both a central component of person-centered care and an indispensable tool for implementing person-centered care in practice. *Knowing*, as described in the interviews, was a broad theme which encompassed several aspects: From a practice perspective, *knowing* consisted of learning about the resident's *life story*, interests and preferences so as to better tailor activities and care tasks to the individual. Moreover, *knowing the person* served to establish a supportive *relationship* between caregiver and resident. At the deepest level then, *knowing* provided an opportunity to promote personhood and maintain a person's identity through the use of life narratives and supportive social relationships.

3.2.1 Life Stories

> "For the other person to be interesting to you, you have to know their history, right? You have to know their life story, and the life story becomes interesting, and it becomes part of what you see in the other [person]… So, to me, person-centered care is really that simple…"
>
> Tove, administration

Using biographical knowledge, or life stories, has been recognized in the literature as a concrete strategy to facilitate the delivery of person-centered care (Brooker & Latham, 2016; Clarke, 2000; Clarke, J. Hanson, & Ross, 2003; Edvardsson, Varrailhon, & Edvardsson, 2014; Edvardsson et al., 2008; Kitwood, 1997; McCormack, 2004). Life stories have been described as able to "uncover much more than people's past lives; they allow an exploration of the most recent past, the present, and people's plans and future concerns" (Clarke, 2000, p. 429). Hence, life stories are able to reveal valuable information about a person, that can drive the care beyond a reductionist task-driven and physical need-based approach, to an approach that recognizes the personhood of the person with dementia (Brooker & Latham, 2016; Clarke, 2000; Clarke et al., 2003; Edvardsson, Varrailhon, et al., 2014; Edvardsson et al., 2008). The use of life stories was a widely accepted strategy across both nursing homes in this study, as described by this care assistant:

> *I know everyone here, one way or another, based on their life stories… so… I know… "oh this one [resident] is like this and that" and if I forget, I sometimes go back and read [the life stories] because yeah… we have to constantly keep ourselves updated, right? And if it's been a while "oh yeah, what was it he liked? What was it he did?" and so you go back and read their journals… and you find... You can pick out something you can use for example*

Hence, as exemplified in the comment above, life stories were primarily used as tools, which, based on findings from interviews and observations, seemed to serve several purposes: (a) they were used to involve the residents in activities that would be meaningful to them; (b) they were used to engage with the residents; (c) they were used to assess and understand residents' needs and behaviours, and; (d) they were used as a care strategy to avoid or reduce 'challenging' behaviours during routine care tasks, such as morning or evening care.

Using life stories to involve residents in activities and engage with them, was described by this care assistant working in an advanced dementia care ward at *Peaceful Gardens*:

> *If you know that the resident has been interested in sports, or has travelled a lot and liked being out in nature, or hunting, or playing guitar or something like that… then it's a good idea to bring that up, bring it up from time to time, even if… maybe you'll get a little reaction, you'll see in in their eyes, or… it's not always you get a reaction, but you try […] As I said, they don't always react positively to it. They don't always understand that you… that they react to what you do. Not always… But all of a sudden you feel that, ok, you see it in their eyes or the way they move, their body language.*

Similarly to what was expressed in the above comment, Brooker and Latham (2016) admit that figuring out what is meaningful, and to whom, can be a difficult task, but they argue that "seeing someone light up with delight when engaged in an activity that has meaning for them is evidence enough that this is a worthwhile endeavour" (p. 100). Later in the interview, the same care assistant elaborated on how life stories guided her practice:

> *It's a part of his life. I think that's person-centered. He's done it for many years so… when you give him the guitar you see that he's still got it… it doesn't always work, but we try… and we have another one [resident] who used to work as a sport journalist, so we always bring him the newspaper… even if he doesn't always read, but he can still turn the pages right? And we also sit with them, one to one contact, and talk.*

Similar to this care assistant, most staff felt it was their task to incorporate what they knew about a resident into everyday practice. Life stories then, were a useful tool for engaging with the residents and attempting to include them in meaningful activities. Here, 'activities' is not necessarily understood as scheduled club activities but rather refer to everyday occupations and opportunities for staff to engage with the residents. For instance, I was able to observe several occasions where staff used what they knew about a resident's background or interests to trigger meaningful conversations during meals or care tasks. This was typical for many staff members, as expressed by an activities coordinator:

> *Of course, we learn a lot by talking to the residents, and getting to know them that way. But it's good to know a little about their background, know like, ok they grew up in Elverum or… they grew up in Tønsberg or something… So that we can bring in some stories and get them to talk a little… If they themselves don't remember that they are from Elverum, you can come with suggestions [laughs] "Did you live there?" and then it's on! [laughs] So that's very important… knowing them.*

Kitwood (1997) recognized that "biographical knowledge about a person becomes essential if their identity is still to be held in place" (p. 56). Similarly, Brooker and Latham (2016) contend that the ability of staff to hold a person's narrative can help residents with dementia maintain their identity and experience increased self-esteem even as dementia progresses (p. 97). Findings from this study's observations and interviews suggest that the use of life stories seemed particularly important in the case of advanced dementia, as they provided a way for staff to support and prompt the residents' life narratives and bring out their individuality when they themselves were unable to do so. As one activities coordinator expressed:

> *We shouldn't include everyone at all costs. It's important to see that Fru Hansen, or him or her, maybe don't think that this is ok. And so it's important to come up with something else… and that's why we have so many different clubs… it's… and we have a lot of CDs… that we can use. So, for example if we hear that "he, he used to listen to a lot of Gluntan[4]" then we bring out a Gluntan CD… because it's not certain that they [residents] are able to remember it themselves, so that's why history is so important.*

Moreover, as brought forth by the above comment, life stories were also used more broadly to organize clubs and scheduled activities that would be interesting for residents to participate in. Using life stories in this way, and the effect this had on practice can be best illustrated by this account:

> *We have this swimming club, with two ladies who go swimming at the local swimming hall. And this, in a way, is about how they… or activities that they wish to have, and have been fond of. So, we are able to tailor the activities we offer towards them [residents] and it's a little bit like… the first time we had it, two of the staff members who had accompanied them came into my office in the afternoon and I started thinking after that "you know what… you don't get any closer to happiness than this" [laughs]. They were so… fantastic in that situation they had in the*

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[4] Gluntan: Norwegian dance band from the 1960s

> *swimming hall. Everything hadn't gone perfectly at all, but it wasn't about that. But that joy and that pride and that commitment that they had in terms of the resident and the situation they had been in, it was really so fantastic to experience that! […] They were so involved, and happy and their eyes were shining, right? Like truly a good day at work […] The best was to see that joy and that pride and the meaning the two co-workers expressed when they were telling me about it… because then I think we see how valuable it is to work with person-centered care also in terms of role, identity and finding meaning in your job… how it, in a way, affects an entire work environment and every single employee.*

The account above reflects two important points: Firstly, it carries important implications in terms of the far-reaching outcomes of person-centered care, specifically because it suggests that person-centered care may have an impact not solely on the quality of life of residents with dementia but also on staff well-being. This is in accordance with a number of studies and systematic reviews that have found some tentative indications of positive effects of person-centered care on staff in the form of increased job satisfaction and personal accomplishment, and decreased stress (Barbosa, Sousa, Nolan, & Figueiredo, 2015; Brownie & Nancarrow, 2013; Pol-Grevelink, Jukema, & Smits, 2012). Secondly, it suggests that this nursing home is recognizing the significance of preserving familiar physical activities. This is especially relevant considering the fact that practices involving procedural memory (for instance, dance and sports) can be conserved in dementia (Castillo, 2011; Taylor, 2008). This second point also speaks to Konto's work on embodied selfhood (Kontos, 2004, 2005; Kontos & Naglie, 2007), specifically the recognition that personhood and identity can be maintained through embodied physical practices (Castillo, 2011).

Furthermore, *knowing the person* through life stories not only resulted in supporting residents in activities, but also provided staff with a certain knowledge and awareness of expressions of the body. In their study on embodied personhood, Kontos and Naglie (2007) found that knowledge of life history made it possible for staff to provide meaning to residents' bodily expressions. Likewise, Edvardsson et al. (2008) posit that knowledge of a person's past can "provide interpretative cues for their present behaviour, needs and wishes" (pp. 363-364). This idea is also supported by Brooker and Latham (2016) who write that ”knowledge of someone's life history may again help staff to understand so-called 'challenging behaviour'" (p. 85). This understanding was apparent for some staff, especially in terms of deriving meaning from 'challenging' behaviours. As one care assistant recounted:

> *For example [resident name] is always quite agitated around 3pm, right at shift change. And I know her very well, and every day, right around that time she gets agitated… and sometimes*

> *aggressive, and you know why? She is thinking that her children are still young and that she has to pick them up from kindergarten… it's always like that, exactly at 3pm.*

What this account powerfully captures is the phenomenon that Kontos and Naglie (2007) describe as "socially acquired habits of the body" (p. 558), that is to say, the manifestation of personhood through bodily expressions and gestures deeply rooted in past experiences, that seem to persist despite the presence of dementia. Similarly, the resident's agitation in the afternoon was recognized by staff as related to the preserved habit of picking up her children from kindergarten. Hence, as depicted in the example above, *knowing the person* disclosed important cues to staff about the underlying meaning of certain behaviours.

Moreover, *knowing the person* provided staff with guidance on how to reduce certain behaviours without having to rely on the use of sedatives or psychopharmaceuticals. For instance, here's how a care assistant working at *Bay Views* described how biographical knowledge had guided their care practice in dealing with a resident's unrest during nights:

> *We had a lady here before… and instead of giving her Sobril, she was used to having a glass of port wine. And she slept on that! And it's much better that she gets alcohol, wine and such, if that's what she's used to. It's a lot better than Sobril*[5] *[...] and she's always lived that way, she's had a glass… and that's what she sleeps on. So that's what we gave her. And I think that's fantastic. Why shouldn't they get that when they end up in a nursing home, if that's what they're used to? What's the point in stuffing them with thousands of pills? So, there's probably many people before, who didn't need all these pills.*

The above comment suggests that biographical knowledge can support alternative care practices for dealing with behaviors, and in so doing reduce the need for 'chemical restraint' and the associated risk of over-sedation. This is in line with the recognition that person-centered care offers an opportunity for moving away from pharmacological interventions for managing behavioral symptoms in residents with dementia (Brooker & Latham, 2016; Edvardsson et al., 2008; Kitwood, 1997). *Knowing the person* also helped reduce 'challenging' behaviors during morning and evening care, as exemplified by this care assistant's description of a typical morning routine with a resident at *Peaceful Gardens*:

> *For example, with [resident name] who's difficult to shower, it helps to remind him that his wife is coming to visit, so then he asks me if he smells and I say "yes you smell!" [laughs] and then we laugh together, and it all goes well… Same thing if he needs to shave, then I say that it doesn't feel nice to give him a hug when it's so scratchy [laughs] and it works!*

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[5] Sobril: medication which acts on the central nervous system - commonly prescribed to treat anxiety disorders, unrest, problems with sleep

What this excerpt seems to reflect is the importance of ‘knowing what makes them tick’ (Galik, Resnick, & Pretzer-Aboff, 2009). The care assistant seemed to know how to talk to the resident, and approach him in a way that would make him cooperate. Having observed interactions between this care assistant and the resident, I know that a close bond exists between the two of them. The conversation recounted above is about more than knowing life stories, it is about knowing the person on a deeper level, and forming a close attachment between caregiver and care recipient. At its core then, findings from the study suggest that life stories provided a foundation for getting to know the person, but that what followed for some staff members was the establishment of a connection, a relationship, between themselves and the care recipient.

3.2.2 Relationality and moving towards relationship-centered care

“For if a disease process causes an intellectual impairment, it is possible for social relations to prevent this becoming a disability.”
(Davis, 2004, p. 376)

Brooker and Latham (2016) raise an important question: “Do our ‘next of kin’ know everything about us?”(p. 98). Indeed, life stories were often provided by relatives, and although useful, some carers felt that the stories were not sufficient in capturing the residents in their entirety. This concern was expressed by some staff, as one care assistant told me:

> *It was a little funny because… we talked about that during the seminar and… that their [residents] relatives are often their children… because they don’t always have spouses… and it’s a little strange that the children are writing their parents’ life stories… because usually they haven’t lived with them for many years [laughs] so relatives don’t always know what kind of routines they [residents] had at home […] because like it says in your life story that you enjoyed cleaning the house, when in reality you didn’t, but your kids saw that you were cleaning the house when they were young [laughs]*

Hence, for some staff, *knowing the person* went beyond simply reading life stories, as exemplified by this care assistant’s account:

> *Well first of all… when I first got here it took some time to get to know them all [residents]… and you don’t have to read all the life stories right away but you can read one or two per day when you have some time. Besides, knowing someone is not just about reading life stories… you have to sit with them and talk. Then they tell you… they remember their childhood, how many siblings, the family they have, what kind of job they had, how they experienced things when they were younger, what school they went to… that way it’s easier to get to know the patient. So it’s*

> *important to sit down with them. Life stories are often written by relatives. But to really get to know (the residents) you have to sit down and be interested in them, and talk to them. Then… because just writing down life stories doesn't help… it helps in the beginning to get to know the patient, in the beginning but… after a while, when this patient lives with us for one or two months, then you get to know everything. Because you're talking and sitting down and… you become acquainted, you've had conversations, you smile to each other… then you start seeing the person differently than the first time they came in to the ward.*

Knowing the person, as portrayed above, requires openness and curiosity. To really know a person, the carer needs to move beyond life stories, and take on an active and reflected role in the meeting with the resident. This account reflects a desire on the part of the caregiver to build a meaningful relationship with the resident. Similar to this care assistant, other staff acknowledged the value in building social relationships with the residents.

Many scholars have recognized the relevance of social relationships in facilitating person-centered care and maintaining personhood. Kitwood (1997) for instance, builds on Buber's work (1937) to illustrate an important point about personhood. The essence of Buber's work (1937) revolves around his identification of two modes of relating with the world, *I-It* (detached and intellectual) and *I-Thou* (engaged and committed) (Kitwood, 1997, pp. 10-12). To Kitwood, as to Buber, to be a *person* is first and foremost defined by the manner in which we choose to relate to one another. It is only by opening ourselves up to the deepest form of relating, *I-Thou*, that we can appreciate one another as whole beings, and recognize the unique value we each hold as *persons*. Hence, Kitwood (1997) describes person-centered care as an approach founded on *I-Thou* meetings, emphasizing the need "to see personhood in relational terms" (p. 12).

Drawing on Kitwood's ideas, Smebye and Kirkevold (2013) argue that "relationships determine the difference between 'person-centered care' and 'individualized care'" (p. 10). In their view, it is through social relationships that personhood can be promoted. This is also emphasized in the person-centered nursing framework developed by McCormack and McCance (2010), where 'the caring relationship' is identified as an essential concept of person-centered care (van der Cingel et al., 2016). Dewing (2008) remarks that the increased focus on caring relationships in person-centered care has prompted a re-conceptualization of Kitwood's ideas and a move towards 'relationship-centered care'. This is evidenced by the increasing number of relationship-centered care frameworks that have developed over the years (Dewing, 2008). Although a complete discussion of relationship-centered care is beyond the scope of this study, there is no denial the relevance relationships have when caring for someone with dementia. Indeed, developing a supportive caregiver - care recipient relationship was recognized by most staff in the present study as an essential part of person-centered care. For instance, one care assistant from *Bay Views* told me about how he decided to approach a new resident who had refused care on several occasions:

> *When [resident name] said no to me, I thought "I respect that, she says no… ok, she says no, well then, I won't do anything" and then she told me "I want milk!", so then I left to go get a glass of milk, "oh, thank you!" she told me… and so we start building a sort of relation. And a couple of days later, I was going to help her and so I tell her "you need to change", "yes fine! Yes ok then" and then she actually cooperated. And so I had broken with… I think that coercion is sort of a barrier to building a good relation, and so by (doing it this way) I've kind of broken that barrier, and then I was able to help her without coercion. But if I had used coercion that first time, when she was new on the ward… she had just arrived. And so I think it would have made it worse if we had used coercion. So working on trust*[6] *is very important.*

The story recounted by the care assistant reveals the perceived value in being patient and taking the time to build a trusting relationship with the residents. This particular resident was considered 'difficult' when she first moved in, but as time went on and a good caring relation solidified, it seemed to get easier for some staff to engage with her. In a case study on the effect of malignant social psychology, Sabat (1994) found that the quality of social relationships were critical in repressing or supporting the abilities of the person with dementia. Indeed, he found that the difference in behaviour spanned "the range from functional and competent in the [day-care centre] setting to dysfunctional and incompetent in the [home] setting" (pp. 161-162) and he contends that these differences in behaviour could not be "explained on the basis of neuropathology alone" (p. 162). This idea is also reflected in this study, as staff acknowledged how *knowing the person* and the quality of the relationship between staff and resident was decisive in mitigating behaviours. Hence, the nature of relationships also guided how the shifts were planned, for instance in terms of assigning staff to residents. These findings are exemplified in the following accounts made by care assistants working in the two nursing homes:

> *For example, the resident I helped today, one time he was very angry, and he's like that with me too sometimes, but one time he was very angry with another [staff] and said "no, get out!" and things like that, and so I went to see him after, and knocked on his door, and I opened the door and he says "Oh is it you? So good that it's you!" and then I felt that I had built a kind of relationship to him… that I was allowed to help him [smile]*

> *We learn all of that from… we're with them so often, so every day we learn something… I know that if I do this, then they get angry or… so I have to not make the situation worse, like… because*

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[6] In Norwegian: Tillitskapende arbeid

> *we know that some of them have very set routines, and if you don't respect those routines, then it all just goes wrong. So, if you know their set routines, and like communicate slowly and you're involved, then it works. It doesn't always work, but most of the time it does yea…*

Penrod et al. (2007) note that it is through social relationships that "caregivers appropriately foster the personhood of those with dementia to build an environment in which they sense being loved; this, in turn, frees them to experience more positive emotional states" (p. 65). Likewise, several staff perceived getting to know residents and having a social relationship with them as critical for not only mitigating behaviours, but promoting resident well-being. Maintaining a social relationship with the residents was recognized as instrumental if certain needs were to be upheld. These needs, as expressed by staff, often overlapped with the psychological needs identified by Kitwood (Kitwood, 1997, pp. 79-85). The five needs – *comfort, attachment, inclusion, occupation* and *identity* – "without the meeting of which a human being cannot function, even minimally, as a person" culminate in the greatest need of all – *love* (Kitwood, 1997, p. 81). According to Kitwood, and echoed in much of the later literature on person-centered care, these needs, although "present in all human beings" (Kitwood, 1997, p. 81), are particularly important for persons with dementia. Interviews revealed that several of these essential needs were considered by staff in their care practice, as exemplified by the following accounts from care assistants at *Bay Views* and *Peaceful Gardens*:

> *When I have a little time to sit with them, and talk to them, and calm them down, and show them love and make them feel safe… because to talk and sit down… talk to them about anything, that gives them 'trygghet'*[7]*… and then they see that "yes, they take care of us", and we get feedback like "you are nice, you are good, you take care of us"… those are the things we hear*

> *With [name of the resident] for example, three weeks ago she was crying in her room, and so I went to see her, and she told me what was wrong […] and she was very upset… so I sat down with her and explained everything […], she cried and I gave her a hug… and then she called her family and told them I had helped her… and one of the daughters, came to me and said "oh you are Gabriel?", "yes" I said, "yes 'du er toppers'['you're great'], mom uses your name all the time!" [laughs]*

These accounts are especially powerful considering the fact that persons with dementia, despite their cognitive impairment, are able to hold on to feelings, emotions, and the ability to relate and socialize. This was beautifully captured by a nurse:

> *Because they have… people affected by dementia have the same feelings, in their entirety, as everyone else. They can get sad, they can get mad, they can get happy, all of these things. Those*

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[7] In English: safety - implies comfort and trust (my transl.)

> *feelings are certainly just as strong for people with dementia. But they just have a little harder time getting around in the world.*

This understanding is particularly relevant to the notion of 'relational personhood', which is underpinned by the recognition that emotional and social interpersonal functions are usually well-preserved in persons with dementia (Castillo, 2011). Castillo (2011) notes that "the cultural meaning of dementia in communities with a relational model of personhood does not entail the loss of the self" (p. 277). Hence, the ability to recognize various dimensions of personhood, opens up to the possibility of stepping away from the narrow conception of personhood as solely emanating from cognitive capacity, and is therefore essential in the context of caring for persons with dementia (Castillo, 2011; Kaufman & Morgan, 2005; Leibing, 2006; Taylor, 2008).

As shown, the idea of a caregiver-care recipient relationship was highly valued by some staff in the wards, and this was also echoed by administrative staff. One administrator at *Peaceful Gardens* recounted a documentary she had seen about a nursing home, to demonstrate this point:

> *What I thought was fantastic about that documentary, is that it really made apparent that relationship. How important it is… and you could really see those staff members who were conscious of that and they were even able to articulate that that's what they were doing. That they were using themselves and they were not afraid of that. They weren't afraid of becoming what we used to call "too private in the care"*[8] *right? They had a very conscious notion of how they were using themselves and what was needed to get that relationship.*

However, while some staff did recognize the value in building a relationship with the residents, it seemed that this was not an easy task for everyone. I myself vividly remember a day when I walked into the ward during an evening shift. Most residents had retreated into their rooms for the night, but there were still some of them sitting – scattered – around the living room. A young care assistant was sitting by himself on the couch, and I couldn't help but notice the distance (both physical and social) between him and the residents. There was no apparent effort on the caregiver's part to engage with the people around him. The place was silent. The key point is this: this moment was certainly not representative of the overall care practice in the ward, but it was also not unusual. Observations also revealed that staff, perhaps unconsciously, had a tendency to chat with one another, without including residents in conversations. Perhaps the biggest issue was the use of mobile phones on the ward and the negative consequences that this

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[8] In Norwegian: 'for privat i omsorgen'

had on interpersonal interactions between residents and staff. One care assistant from *Bay Views* powerfully outlined this issue:

> *I have seen so many subs [‘ekstravakter’], sitting… ai, ai, I get so angry, I might boil over. They sit on Facebook, while they’re feeding them like [gestures]… what kind of contact does one have with the person in that situation? Where is the care? How do you see that person? You see Facebook! [knocks on the table]. I’ve seen so many like... so many. When you’re at work, you’re at work. And it’s like I say... you’re not ’nærværende’*[9]*, you don’t get these moments, you don’t see what the resident needs, you’re not present and aware of what is going on around you... that phone needs to go. How many times have I not caught someone in the laundry room, chatting away?*

In their study on the influence of relationships on personhood, Smebye and Kirkevold (2013) identified both ‘professional’ and ‘unprofessional’ relationships in the context of nursing home care. ‘Unprofessional relationships’, which undermined personhood, were described as task-driven, routine care practices where caregivers “did the necessary ‘bed and body work’ but did not invest in the relationship with the person with dementia” (p. 8). The authors speculated that keeping a distance from the resident could be a coping mechanism on the part of the caregiver. This issue was reflected in some of the interviews with staff, as exemplified by this administrator’s account:

> *If you don’t dare doing that… if you don’t dare to recognize how important that relationship between you and the resident is, then I don’t think you’ll get very far! And of course it’s really scary! Because, in a way, you have to open up a little bit. You can’t have that glass wall between you and the resident… when we walk around here and talk about this being a “home”… then staff can’t be walking around here acting like… or… they have to kind of respect that they are walking into that “home”.*

In spite of this, there were numerous examples of close bonds that had evolved between caregiver and care recipient. I witnessed warm and affectionate interactions between staff and residents, spanning anything from holding hands and hugging, to laughing together or simply sharing a moment in each other’s company. Some staff even described residents as becoming ‘family’. Similar to *seeing the person*, *knowing the person* was perceived as important in bringing the person to the forefront. In a sense, knowing the person and being in relation created a condition whereby the residents could be seen and acknowledged as *persons*. In turn, being able to *see the person*, was instrumental in being able to build a connection with the residents. Moser (2011, p. 716) posits that a “relational approach to life and dementia offers wider

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[9] In English: Present – implies a warm and close presence (my transl.)

possibilities for actions in terms of care, patient agency, and subjectivity than somatizing practices". Indeed, *knowing the person* served several purposes for the staff: it helped contextualize the residents' behaviours, and in so doing, informed their care practices. It also allowed the institution to plan appropriate activities that would match residents' interests. Additionally, it provided a foundation for building a relationship between the carer and the care recipient, which again facilitated the daily care practices, especially in more delicate situations, such as showering and dressing. At its core then, *knowing the person* and the care practices that ensued, were essential in supporting the psychological needs of the residents, in terms of *attachment, occupation, inclusion, comfort* and *identity* (Kitwood, 1997). Most importantly, 'being in relation' was perceived as vital for supporting residents' personhood. Indeed, through their description of caring relationships, several staff seemed to acknowledge personhood as something that is not solely sustained by cognitive capacity, but rather brought forth through *relations*. This resonates strongly with Taylor's (2008) plea in her 'autoethnographic' essay "On Recognition, Caring and Dementia":

> Everyone becomes impaired in one way or another, unless we die first. Every human being begins life utterly reliant on kindnesses he can neither remember nor repay, and many of us will end our lives in a similar state [...] why then should a person be cast out and abandoned, condemned to social death, and denied recognition as a friend, a person, a fellow human being, just because she shows signs of succumbing to the same forces that we know will eventually claim one of us? Can we not resist this "erosion of personhood" (Luborsky, 1994), and "overcome the notion that cognition is the decisive carrier of personhood?" (Leibing, 2006:258)?
>
> (Taylor, 2008, p. 333)

I will now turn to another way staff perceived as important in promoting personhood. The last theme of this chapter, entitled *Empowering the person* is undoubtedly linked to the two previous themes presented in this paper, but involved slightly different processes in practice. These will be presented in the next section.

3.3 ON EMPOWERING THE PERSON

> "They're still able to do a lot and we shouldn't take that away from them [...] Because imagine just sitting there, and being able to wash yourself, but instead we do it just because it needs to go fast? So that's very important... that we don't take away what they can. That's very important, not taking away what they can"
>
> Maja, nurse

Many of the staff members I interviewed used the Norwegian term ‘mestring’, or a derivative of this term, when talking about features of person-centered care. This term and its various forms, ‘å mestre/mestringsfølelse’, although frequently used in Norwegian healthcare and nursing literature, carries no direct translation to English. ‘Mestring’ is often equated to the English word ‘coping’, which denotes the attempt or ability to overcome challenges (Merriam-Webster, 2018). However, the Norwegian term carries a broader meaning. Citing Vifladt and Hoping (2004), the Norwegian directorate of health and Social Affairs (2017) describes ‘mestring’ as experiencing strength to tackle challenges, and having a feeling of control over one’s life (p. 7). In the context of this study, staff used phrases such as *“få oppleve mestring”* or *“hjelpe dem å mestre hverdagen”*, both implying that their role is to help and support residents with dementia in attaining, or experiencing, a feeling of ‘mestring’. Gedde-Dahl (2001) suggests ‘styrking av mestring’, which directly translates to ‘strengthening of *mestring*’, to be the Norwegian equivalent of ‘empowerment’. I therefore argue that ‘empowering’ and ‘empowerment’ are more suitable and relevant terms to describe staff’s actions and the relational dynamics between staff and residents in the present study. The term ‘empowerment’ has been utilized and described by many disciplines, and defining attributes and applications of the term will vary depending on the context in which it is used. Although no single definition of the term exists, Ellis-Stoll and Popkess-Vawter (1998) identify ‘power’ and ‘control’ as central aspects of empowerment. Within the context of health, the WHO definition seems like an appropriate starting point. The WHO defines empowerment as a ‘process’, whereby an individual is able “to make decisions and have control over their personal life” (WHO, 1998), a notion that closely approximates the meaning of ‘mestring’.

In their concept analysis of person-centered care and person-centeredness, Morgan and Yoder (2012) and Slater (2006), respectively, found *empowerment* to be a defining attribute in the delivery of person-centered care. In relation to dementia care, Martin and Younger (2000) note that there are many routes to empowerment, but consider ‘the nurse’ as central in this process. The authors conceive of the caregiver-care recipient relationship as “double-edged”, holding the potential to be both empowering and oppressive (p. 60). Furthermore, Brooker and Latham (2016) describe empowerment as a process that requires the caregiver to “let go of control” (p. 142). Zimmerman (2000) writes that “both empowerment processes and outcomes vary in their outward form because no standard can fully capture its meaning for all people in all contexts” (p. 45). Indeed, whether a person feels empowered, or actions are empowering, is entirely context-specific. In the context of this study, *empowering the person*, was centered around supporting residents in leading an ‘everyday life’ through the promotion of a sense of autonomy and agency. The essence of empowerment was succinctly captured by a nurse working at *Peaceful Gardens*:

> *But I think it's also about how we formulate things, right? And how we optimally use peoples' life stories, what they like, what they don't like, and try to allow them to do what they manage on their own, without impinging on them and take away the resources they have left. It's about them leading an everyday life. So they can be… I mean despite… I usually say that if someone breaks a leg then they need crutches, so when someone breaks their head then they also need some help to get around […] But it's kind of… We're supposed to help them when they need help but we're not supposed to like… I mean they're not kids. They are grownup people. And they should get the help they need but not… we're not supposed to take their life away.*

As evidenced in this quote, and throughout the analysis, *empowering the person* is inextricably linked to the first two themes discussed in this chapter, *seeing the person* and *knowing the person*. For instance, Martin and Younger (2000) posit that a holistic approach to care is needed in order to foster an empowering culture of care. Hence, it can be argued that processes involved in *seeing the person* and *knowing the person*, represent paths towards empowerment for the residents. However, for the purpose of clarity, I present *empowering* as a separate theme. As opposed to *seeing the person* and *knowing the person*, the strategies involved in *empowering the person*, were depicted as more concrete to implement in practice. As described by staff, *empowering the person* could be achieved through several strategies, including *not taking over* and *being in the now*.

3.3.1 Not taking over: supporting functional abilities and decision-making

Not taking over, as depicted by staff, was predominantly related to interactions that occurred during personal care or around mealtimes, but to some extent was also related to activities outside of routine care tasks. Essentially, *not taking over* was understood as a way towards (1) supporting remaining abilities and (2) promoting choice and decision-making in the residents' day-to-day life. Central to this theme lies the idea of control, or rather the ability of staff to give up control, in favour of the residents. Aggarwal et al. (2003) remark that staff routinely hold considerably more power than residents with dementia in the nursing home context. Furthermore, the authors note that the presence of this power imbalance in itself can be disempowering for residents (Aggarwal et al., 2003). In the context of this study, staff seemed to be aware of the power relations that existed between themselves and the resident, and in some cases, their practices reflected a conscious approach to take this power imbalance in consideration during care tasks. For instance, some staff strived to avoid the use of excessive control and paternalistic communication, as exemplified by these accounts made by a care assistant and a nurse:

> *One of the residents I worked with used to be a bank manager… so we have to understand how they were before. Imagine, someone who was maybe used to be in charge, and then they end up here, and all of a sudden, I'm supposed to be the one bossing him around? [laughs]… am I supposed to say, "brush your teeth!", "go to the bathroom!"? … imagine!*

> *Maybe it's a good idea to give painkillers in bed, like we did today with [resident name], then it's first give the painkillers and then wait for [resident name] to get out of bed and come out of her room… Because she doesn't want to get up because of the pain, the same thing happened yesterday. So, it helps, and the day is completely different. There's no point in me saying "oh you, you need to get up because I want you to!" What I want is not important!*

These accounts are particularly important considering the fact that providing a sense of power and control to persons with dementia has been identified as a central aspect of person-centered care (Edvardsson et al., 2008). Moreover, *not taking over* was premised on staff's capability to know and focus on the residents' preserved strengths and resources, rather than their limitations. Penrod et al. (2007) describes the need for careful adaptation of the social and physical environment to "capitalize on preserved strengths" of persons with dementia (p. 68). Furthermore, Brooker and Latham (2016) note that "not allowing people to use the abilities that they have is disempowering in the extreme […] the right amount of support will enable someone to feel empowered" (p. 156). In a similar fashion, staff in this study displayed an understanding of how to adapt the environment to the resources of the individual, particularly through the use of appropriate verbal and gestural guidance. For instance, one of the care assistants at *Bay Views* described how she carefully tailored activities of daily living to the abilities of the different residents:

> *If the patient is able to manage on their own, then it's very important that they maintain those abilities. It's important to me… or on the ward, that they are able to maintain their everyday life, and their routines. There's a difference between someone who is 'oppegående' [able to move around] and someone who is bedridden. And we also have people who are able but who lack orientation…for example, we can give her [resident] a cloth, here you go, wash your face. Even if I show her with my body language how she should wash her face, she doesn't understand. And so, even if I try (not to take over), I have to help her. But at the same time, I tell her and inform her of what I am doing… But for example [another resident name], she manages on her own, but she doesn't really do things in the right order. So, I just guide her and then it's ok, she can do it on her own. So, I don't need to wash her. But if she needs help, for example she can't reach behind her back, then I help her with washing her back. But it's important that she maintains those abilities, and uses her body and her hands.*

As expressed in this account, careful consideration of each resident's abilities was paramount in guiding the degree to which the care assistant would *take over* the care, or let the residents do it themselves. According to some staff, meals also provided another situation where caregivers could emphasize and support residents' functional abilities, as recounted by an activities coordinator:

> *You can think that "Fru Hansen" won't be able to put spread on her slice of bread… but through facilitation and a little bit of help it works. You can help with some of it, and then she can do the rest on her own. And then you (the resident) have… you have that sense that you were able do it on your own… or… yea… we try to preserve that. I think that's very important. And that's one reason for those breakfast groups. We have to try to preserve those abilities… that's important. As an activities coordinator, you have to try to preserve those skills and emphasize their abilities… and the individual resources, not… not all the limitations, but really see the resources that are present.*

In some cases, staff went beyond the context of routine tasks to promote residents' remaining abilities. For instance, some residents were encouraged to engage in hobbies or interests, as exemplified by one care assistant working at *Bay Views*:

> *Its... that we don't take away what they can. I don't know if you've heard that [resident name], that handsome man, he plays the piano. He sits like this and he plays [gestures]. And we had this lady, she's gone now, but she danced. So, she would entertain while he sat and played. And we had an artist, who used to paint. So, it's important, to get to know what they've done. You can be so startled when all of a sudden… you see a lady like [resident name] sit and paint! So, it's really important that they… no really, I was so shocked when I saw her paint, because we didn't think she could. And she danced! She got up from her wheelchair and… [laughs]*

Events in which residents with dementia are encouraged to keep up their past interests and hobbies are not only important in maintaining their level of functioning but also provides an opportunity for holding their identity in place. Hence, situations as the one described above, holds the potential to satisfy both the needs for *occupation* and *identity* described by Kitwood (1997, pp. 83-84). Alongside the interviews, my observations in the field revealed countless examples of how care assistants and nurses supported residents remaining abilities, especially during morning care or meals. For instance, I recall care assistants encouraging residents to brush their teeth or comb their hair on their own, and *taking over* only when their assistance was needed. In relation to meals, *Peaceful Gardens* in particular, was very conscious of the value behind letting residents prepare their own sandwiches for breakfast, allowing for both remaining abilities and decision-making to be supported. However, this awareness was seldom enough to make it a systematic routine, and seemed to be related to the number of staff available at breakfast and their degree of knowledge of the residents.

Central to Kitwood's (1997) work on person-centered care was his identification of care practices and interactions that could either undermine or nurture personhood, which he respectively termed 'malignant social psychology' and 'positive person work'. Much of what has been described so far in this section can be equated to some of the 'positive person work' interactions identified by Kitwood, specifically, 'collaboration' and 'facilitation'. Similar in nature, these two types of interactions involve caregivers and care recipients working together on common tasks, emphasizing the active involvement of the person with dementia, with the caregiver cast in a role of assistant or helper. Whilst 'collaboration' emphasizes the notion "that care is not something that is 'done' to a person" (Kitwood, 1997, p. 90), 'facilitation' requires sensitivity on the part of the caregiver to assess the degree to which a person with dementia requires support and respond accordingly to enable an action to occur. However, as mentioned earlier, *not taking over*, was not only a strategy towards supporting the functional abilities of residents but also served to promote choice and involve them in decision-making processes. The work done by staff in this regard closely aligns with another positive interaction, described by Kitwood as 'negotiation', which posits that consulting people on their wishes and preferences serves to shift the balance of power back to the person with dementia (Kitwood, 1997, p. 90). Indeed, care practices that emphasize offering choices to residents have been identified as a route to empowerment (Martin & Younger, 2000). Care routines reflecting features of both 'collaboration/facilitation' and 'negotiation', were described by a care assistant in the following account:

> *It's person-centered care! The residents are actively involved in their own everyday lives and we help them maintain their functional abilities for as long as possible […] I think, what can I do to help that person feel a sense of ownership over their own life? It's the small things. It's to let them choose what they want to eat, that's one of the things… or when they want to get up in the morning… of course I know that we shouldn't let them sleep all day, that's not good either. But we have to cooperate and let them be in charge of their day as much as possible. It's about picking their own clothes in the morning… "these two… the red or the blue? [mimes with her hands] "I want the blue!" well then, I give them the blue [laughs] And I let them put on their shoes on their own, instead of me just doing it because that would be faster… I let them do it! Because that's 'mestring' ['empowerment']. I know for example that if their pants are here [shows height at knee] they may not be able to pull them up, but if I put their pants up to here [shows a little higher, at the level of her thigh] then they can do the rest on their own…*

Hence, as exemplified in these previous accounts, staff found very concrete strategies through which they strived to encourage residents to partake in tasks and decision-making surrounding personal care. Similar to how staff adjusted the degree of support they provided to residents' level of functionality, choices were adjusted to residents' ability to make informed decisions, so that they could feel that they were part of the decision-making process, yet without being given unlimited freedom to choose. Previous studies show that narrowing the range of available choices is a strategy that helps to promote autonomous decision-making for persons with dementia (Helgesen, Larsson, & Athlin, 2014; Smebye, Kirkevold, & Engedal, 2012). Moreover, staff's conscious efforts to involve residents in the decision-making, rather than taking over, is particularly important considering that lack of choice has been identified as a source of dissatisfaction for persons with dementia (Aggarwal et al., 2003).

3.3.2 When staff take over: learned helplessness

Thus, findings from interviews reveal that *not taking over* by handing over control to the residents was central to staff's understanding of person-centered care. However, certain conditions related to the nursing home context or individual staff made this more difficult to achieve in practice. Observations revealed that while some individual staff members were conducive in supporting participants use of remaining abilities, this was seldom always the case. For instance, *Bay Views* was organized in such a way that staff always prepared breakfast sandwiches for everyone on the ward, although some residents would have been capable of doing it themselves. In this sense, staff *taking over* the breakfast preparation provided a missed opportunity for some residents to utilize their abilities. Additionally, in relation to supporting choice and decision-making, observational findings from both nursing homes, reveal that whilst some choice was offered to residents in terms of what clothes to wear, what spread to put on their slice of bread, or (to a certain degree) when to get up in the morning, resident involvement in bigger decisions, such as how they wanted to spend and structure their day, was not often encountered.

Hence, although staff expressed the importance of not taking away residents' remaining resources, whether in terms of functional abilities or participation in decision-making, the work environment provided limited conditions within which this could be fulfilled to the fullest. Although this chapter is focused on individual staff understanding and care strategies, a short discussion of the broader organization of practice is warranted in this section, since findings seem to suggest that conditions related to convenience, time constraints and culture of care were decisive in determining the degree to which staff would *take over* task completion or decision-making. For instance, the same care assistant that had talked about "the small things" that could enhance a feeling of ownership in residents, later revealed that she didn't always succeed in *not taking over*:

> *It's the small things… that could be quicker for me to do, and sometimes I do it because of time pressure… we're not so many here… so sometimes we have to do things because they need to get done anyway*

Her account resonates with Brooker and Latham (2016), who recognize that "it is very easy in busy environments to take over a person with dementia completely" (p. 156). References to time constraints as impeding on person-centered care practices have been well-documented in the literature (Aggarwal et al., 2003; Brooker & Latham, 2016; Colomer & de Vries, 2016; Helgesen et al., 2014; Moore et al., 2017; Talbot & Brewer, 2016), and will be discussed further in Chapter Four. However, some interviews also revealed that *taking over* may not only be an issue of busy work environment, but rather lies deeper, within the institutional culture of care, as suggested by this nurse working at *Peaceful Gardens*:

> *I think there are still those who think it doesn't matter as long as the residents are clean and cute, and that they're able to help them, because "they're so good at helping" [using a baby voice]. We are all motivated for selfish reasons, in one way or another right? Especially in the health care system… there's a lot of people who work here because they are looking for that validation that they are nice and sweet. And then there are some of us who don't really give a damn about that [laughs]. But you know? If that's what motivates us, then oh we're so nice and sweet because we tuck them (residents) under a blanket, give them a pat on the cheek and some pureed food... but I think that culture of care is a big challenge, because we're promoting learned helplessness right? It's this culture of like, "I'm so very sweet and nice because I'm helping the helpless, but god forbid if I help the helpless become more self-reliant, because then I'm not that nice" [laughs]*

In contrast to the previous statement made by the care assistant, this account shifts the focus from organizational and practical constraints to more deeply rooted issues within personal attitudes and the culture of care. A more extensive analysis of the broader institutional caring environment and its resulting implications for those who provide direct care to residents will be discussed in the following chapter. However, it is important to note that 'excesses of care' as described above, risks restricting 'a patient's room for action' and in so doing, contributes to the asymmetry of power in the caregiver-care recipient relationship (Delmar, 2012). Indeed, it can be argued that these two accounts illustrate episodes of 'disempowerment', described by Kitwood (1997) as events in which persons with dementia are not allowed to use the abilities they have (p. 46). Brooker and Latham warns that providing "too much support can make people feel angry or stupid" (Brooker & Latham, 2016, p. 156). Furthermore, in line with the nurse's account, findings indicate that overriding a person with dementia can lead to learned helplessness and thus precipitate functional decline for persons with dementia (Aggarwal et al., 2003; Sabat, 1994; Smebye et al., 2012).

3.3.3 Being in the now

Another subtheme that emerged from the interview analysis is what I have chosen to call *being in the now*. To my knowledge, this theme does not directly relate to any concrete elements of person-centered care. Nevertheless, it is valuable to present here because it emerged as a considerable finding from several interviews and, as I will argue, does relate to the overall values upon which person-centered care is built. As I will show in this section, *being in the now* refers to a relative 'now', carrying two separate meanings. Thus, the first part of this discussion centres around staff's ability to meet residents in the actual present 'now', whilst the second part delves into staff's ability to accept the 'now' as experienced by residents, mostly as a past in the present.

Kitwood (1997) writes that the first requirement of a caregiver is to be "actually present, in the sense of being psychologically available [...] being present with and for another person, without distraction from outside or disturbance from within" (p. 119). To a certain degree, *being in the now*, as conveyed by staff, resonates with what Kitwood calls "being present". As one nurse expressed:

> *I think that it can be as simple as just making eye contact, saying "hello Norman, hello Per, good to see you, good having you here..." I mean, that you acknowledge their presence, and meet them in the moment. I think simply that, is person-centered.*

Indeed, *being in the now*, was mainly depicted as a care strategy involving staff's ability to focus their attention on – and respond accordingly to – what is happening in the present moment with a particular resident. As Brooker & Latham (2016) write "when impaired cognition makes it hard to orient yourself in the present, imagine the future or recall the recent past, it is the *moment* that matters most of all" (p. 110). Echoing this thought, one care assistant from *Peaceful Gardens* described:

> *It's, it's, it's like I'm thinking, that we shouldn't see the residents based on their disease, but what he or she needs daily! **Today**. I treat day by day. Today is today. If today they want to go*

> *to bed at 7:30, then I say "but, it's a little bit early" but if that person really wants to go to bed then 'vær så god' ('of course'). You understand? That's person-centered […] And we don't wake anyone up if they don't want to get up [laughs], you understand? […] and I've heard horror stories where they [staff] they come at 7am and knock on doors [mimes with her hands] "get up, get up, get up, wake up, wake up, wake up" … we don't do that here […] because for everyone here we have the same routines. Dinner at the same time, giving out medications, everything… but I'm more concerned with seeing what each individual… I'm more concerned with what is happening in that moment… with that individual [knocks on the table] now! It's not what you do in an hour, or what you did one hour ago, but what's happening in the now! That's what matters. […] And I think that's person-centered care, when we focus on the person, not just the everyday routines*

In other words, *being in the now* could be described as staff's attempt to be 'tuned in' to a resident at a particular point in time. However, as another care assistant from *Bay Views* seems to suggest, not everyone in the ward had the ability to *be in the now* with the residents:

> *They think "oh I have 4-5 that I have to take care of, and I have to serve food and breakfast and everything and clean-up and other tasks are waiting for me. So I do it fast tsk tsk" that's how they think. I prioritize the patients. The person I'm standing with now, that's my priority. The rest can wait. If I don't make everything I had to do that day, the others who are coming after can take over. I'm standing with that patient... so it's important for me to... be present and be focused on that patient. Talk, say things in the right order, show them, show them how much they can.*

The previous accounts resonate with Kitwood's thoughts on "being present", as he maintains that this way of being "entails letting go of that obsession with *doing*, which often damages care work, and having a greater capacity simply for *being*." (1997, p. 119). Here, as in the previous accounts, the individual's routine, rather than the institution's routine, should be the focal point for guiding caring practices. It can be argued that *being in the now* with the resident, as described in the two previous accounts, constitutes a route towards resident empowerment, as staff strives to put the individual first, respecting the individual's needs and wishes and understanding that these needs and wishes may change from day to day. Allowing for this form of flexibility in a work environment usually governed by routinization and standardization, is of particular importance considering how, in the literature, routinization of care has been criticized as a means towards professional control (Hill, 2008; Kitwood, 1997).

As mentioned in the introduction, *being in the now* also carried another meaning. Indeed, in a few other instances, *being in the now*, could be described as staff striving to align themselves with residents' conceptions of reality. When used in this sense, *being in the now,* illustrated the carers need to respect a person's sense of time and place. Essentially, this process was dependent on staff's ability to move away from trying to control a resident's conception of reality, to fully accepting it. Referencing Garratt and Hamilton-Smith (1995), Hill (2004) writes that "rather than bringing the person into their reality, carers must work with the person in constructing a reality which is meaningful and makes sense to the person him- or herself." (p. 57). Similarly, as this nurse explained:

> *Yes, I too sometimes believe that reality orientation is useful, if that's what someone asks for… but I don't think we're supposed to be imposing/threatening*[10] *our reality upon them (residents) all the time*

In this second sense then, *being in the now*, seemed to closely align with 'validation', a central element of 'positive person work' in person-centered care, described as the ability to accept and acknowledge a person's frame of reference (Kitwood, 1997, p. 91). For instance, 'validation' is also listed as a key person-centered care indicator in Brooker & Latham's VIPS framework (2016), and has been recognised as a basic principle of care by other scholars in dementia care (Hill, 2008). Pitkin (2016) contends that using validation, enables carers to better understand the experience of the person with dementia, and in so doing, can guide their care practices to meet that person's strengths. Similarly, Edvardsson et al. (2008) note that attempting to rectify the experienced reality of a person with dementia, runs the risk of creating "destructive feelings of insecurity and anxiety" (p. 364). Hence, it is not unreasonable to theorize that successfully accommodating a person's reality, by *being in the now*, carries the potential to enhance a sense of continuity of self for the person with dementia, thereby advancing well-being and preventing feelings of disempowerment.

With reference to Goldsmith (1996), Martin and Younger (2000) contend that both the dementia condition and other peoples' reactions to the condition, are disempowering for the person with dementia. By supporting resident participation in decision-making and personal care for instance, staff attempted to foster a feeling of 'mestring' ('empowerment') in the persons they cared for. However, these "surface niceties" as Innes (2009, p. 97) terms it, may not be enough to establish a truly empowering culture of care. Indeed, she contends that current institutions continue to exhibit a culture of control, partly due to the irreconcilable nature of a flexible person-centered approach to care with that of an institution in charge of protecting their residents, and thus restraining potential freedoms to avoid any risks. This complex balance between empowering residents to live an everyday life while holding on to control to avoid any

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[10] In Norwegian: å true

risks to residents or the institution was a familiar source of concern for some of the staff I interviewed. Consider for instance this exchange I had with one of the care assistants:

G: *I always used to tell my former boss that I'm going out for a walk with this resident… but I don't do that here*

I: Why not?

G: *Because I don't know the people here so well*

I: The people living here?

G: *No the bosses and the staff. But at my old job, I knew everyone so there was never any issue. I could just say "bye I'm going now", and then I would go for a walk with a resident, and there was no issue. Here, if I do that, oh my god*

I: So you're scared of doing something you think the resident would actually benefit from?

G: *Yes, scared yes… because if I leave, and something happens here, like a fire, or a patient falls or… then I'm responsible because… where is the staff? They say… if something happens, and I'm away… "Where is Gabriel?" "Gabriel is out with"… then it's like "why wasn't he here?"*

Hence, although the ideal expressed by staff was to empower residents by promoting a sense of autonomy and agency, there was seldom room for such an endeavour. A more thorough discussion on the role of the larger organisational environment and its consequences for person-centered care practice will follow in the next chapters.

3.4 CONCLUSION: translating theory into individual practice

The first main finding that emerged from the analysis was that the knowledge of person-centered care was not systematic, and seemed unevenly distributed across levels of staff. For instance, because a few care assistants did not know the term 'person-centered', they spoke of what they thought constituted 'good care' instead. Furthermore, although most of the other care assistants had heard about person-centered care, very few had received explicit training – whether formal or informal. As a result, some care assistants displayed apparent deficiencies in their understanding of person-centered care and a few were unaware of whether or not they were actually working in a person-centered manner. On the other hand, interviews with administrators, nurses and activities-coordinators suggest that these groups of staff (with the exception of a few care assistants) have a better grasp on the meaning of person-centered care. Hence, a gap existed between the theory of person-centered care and the various staff's understanding of what this theory encompasses. Similar findings have been reported elsewhere in the literature (Colomer & de Vries, 2016; Hunter, Hadjistavropoulos, & Kaasalainen, 2016; Talbot & Brewer, 2016).

However, although not all participants had taken part in any systematic or formal training in person-centered care, it seems that their intuitive understanding of what constitutes 'good care' or 'person-centered care' shared some similarities with the fundamental theoretical insights of a person-centered care approach. This finding is in line with a number of other studies that have underlined the universality of person-centered care (Brooker & Latham, 2016; Colomer & de Vries, 2016; Edvardsson et al., 2008). Moreover, many staff members described person-centered care, as 'commonsensical' and 'logical', guided by common human values such as respect, empathy and openness. As expressed by one nurse at *Peaceful Gardens*:

> *Well I think… What I really found so nice about person-centered care is that it's actually the practice that you all of a sudden get a theory on! [knocks on the table]. Instead of the other way around you know? Because it's what we know works, and then someone just said that that's the way it is! [knocks on the table]*

Despite a vast disparity in how person-centered care was defined and adopted by the different staff members, I argue that the notions of *seeing the person*, *knowing the person* and *empowering the person*, as collectively conveyed by the participants, do reflect a person-centered perspective. Firstly, – and in accordance with the Enriched Model of Dementia (Brooker & Latham, 2016, p. 19) – all the themes and subthemes described above, emerge from staff's perception of the dementia experience as shaped by more than neuropathology alone. Secondly, the themes in this chapter reflect a tendency to move away from conceiving of cognitive capacity as essential to 'being a person', instead broadening and valorising other notions of personhood. Secondly, these themes and the care practices they entailed were, to a certain degree, conducive in supporting the basic needs identified by Kitwood (1997, p. 82) – *attachment, inclusion, occupation, comfort* and *identity*. Furthermore, some of the care strategies described in this chapter, such as understanding behaviours as 'responsive' rather than 'challenging', using life stories, and supporting resident's remaining abilities and decision-making, have all been identified as aspects of person-centered care (Brooker & Latham, 2016; Edvardsson et al., 2008; Kitwood, 1997). Hence, interviews revealed that most participants had an underlying (and at times intuitive) understanding of what it means to be person-centered, and an ability to bring forth the various dimensions of residents' personhood through different care strategies.

Another important question arises from the findings and discussion in this chapter, namely: To what extent did staff do what they say they do? In an ethnographic study examining how person-centered care was defined and practiced in a dementia care setting, Doyle and Rubinstein (2013) found that "there was a tendency to unconsciously revert clinical practice to the more commonly held biomedical model", despite staff having received training in person-centered care (p. 956). Similar to these findings, observations carried out during my own fieldwork revealed that translating staff understanding into actual practice was difficult to achieve. For instance, although there seemed to be a reluctance on the part of most participants to approach and define a person by their condition in the interviews, care practices I observed were not always suitable in bringing 'the person' to the foreground. Similarly, while many staff acknowledged the importance of building a relationship with the residents, and a few had managed to form close bonds with them, this was not always apparent in practice. This was particularly evident during weekend or evening shifts, when subs, who didn't know the residents well enough to meaningfully interact with them, were working. Also during weekdays with full-time staff, residents with higher functionality seemed more included than others. Furthermore, while staff recognized the importance of supporting residents' remaining abilities, this was sometimes ignored in order to 'get the job done' as quickly as possible. Another main finding then, was that the knowledge staff had, whether acquired intuitively or through training, was not sufficient in enabling a sustainable and committed approach to person-centered care in practice. In other words, I contend that a gap existed, not only between person-centered care theory and staff's understanding and knowledge of person-centered care; but also between the acquired knowledge on person-centered care and the systematic implementation of this knowledge in practice. Yet, despite these disparities, certain aspects of person-centered care were upheld by individual staff members. The situation regarding person-centered care practice in both nursing homes, is captured in the following account by an administrator:

> *When I first started here, I noticed that the physical environment was in place, but at the same time, I felt like we weren't necessarily any better at person-centered care here than in other nursing homes I've been. I would claim that the ward… one of the wards at [another nursing home], is better at person-centered care than what I experience we are here… if we're just talking like… 'ta alle over en kam'*[11]*. Because there's absolutely people here who are 'knallgode' ['outstanding'] and there are many who have it in them, and who do it… but who*

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[11] In English: "measure everyone by the same yardstick" (my transl.)

> *don’t know that they are actually doing it. But on average I think… I was surprised that we weren’t better at person-centered care here, because I thought that was ‘helt spikra’ [really ‘nailed down’].*

Hence, in some instances, care practices seemed to fall short of the person-centered care model, and the care strategies that did reflect a person-centered approach were not systematically implemented. According to some staff, this gap was a consequence of specific challenges they encountered in their work environment. The challenges faced by health professionals and the required transformations to enable a systematic implementation of person-centered care will be explored in the next chapters.

CHAPTER FOUR:

THE IMPLEMENTATION OF PERSON-CENTERED CARE

- FROM THEORETICAL IDEAL TO INSTITUTIONAL PRACTICE -

> On busy days like today, it seems that it all boils down to staff having enough time to take care of the bare necessities, like eating, showering and dressing.
> On busy days like today, I am mostly sitting on my own in the living room, while the people working here are running around in all directions.
> On busy days like today, I can feel their stress and exhaustion on my body.
> On busy days like today, it seems almost crazy to expect each person living in this facility to be "seen" at all times.
> On busy days like today, there are so many other tasks that appear to be prioritized by the institution and its staff.
> On busy days like today, it seems that ideas of how to organize the workplace - even though these are based on person-centered care theory - are a burden in disguise.
>
> Take the food-making for example, the idea is to make the ward feel as close to a home as possible. The idea is that staff and residents work together, to prepare the food. Whilst this, in theory, is a good idea, there seems to be several issues with actualizing it in practice. What happens on the days (which seems to be most days) when residents don't feel like participating? The immediate result seems to be that staff are left to do the grocery shopping and cooking on their own… missing out on valuable time that could have been spent with the residents. I started fieldwork thinking the main issue was a lack of staff training and understanding, and whilst this might still be a considerable concern, I see now that problems related to resources, time, task-driven routines and organization of tasks cannot be disregarded.
>
> (Excerpt from field notes, Peaceful Gardens, Oct. 2017)

The previous chapter provided a descriptive analysis of how staff at the two nursing homes understood person-centered care, and how this understanding, in turn, informed their daily practice. Hill (2004) writes that "the difficulty with person-centered care lay not in the theory but in its implementation in the 'real' world of care" (p. 63), a notion that seems to resonate with the findings presented in Chapter Three. Indeed, while some staff I interviewed proved to have a high level of knowledge about the meaning of person-centered care, others demonstrated an intuitive understanding of person-centered care through their description of what they thought constituted 'good care'. Hence, the meaning of person-centered care as described by staff, in many ways, overlapped with the theory of person-centered care as presented in the literature. However, the knowledge expressed in the interviews was not always apparent in their practice. At the individual staff-level, observations revealed a piecemeal approach to the implementation of person-centered care in practice. At this point, addressing the reality of the work environment could shed light on the gap identified between staff's knowledge of person-centered care and the enactment of this knowledge in practice. As will be presented in this chapter, interviews and observations revealed that staff had differential, and sometimes conflicting, perceptions of the challenges they faced relating to working person-centered. One element that seemed to guide staff's perceived challenges was their individual understandings of person-centered care. Moreover, the perceived challenges were especially different across professional roles, as each level of staff seemed to experience the issue of implementation in very contrasting ways. In some instances, this led staff to engage in a blame game across the different levels of the organisations. Since the challenges identified by staff extended to multiple levels of influence, it seemed appropriate to organize my findings and discussion along these identified levels. Hence, the aim of the present chapter is to delve into the individual, interpersonal, organisational and national levels of influence on the implementation of person-centered care at *Peaceful Gardens* and *Bay View*.

4.1 CHALLENGES AT THE INTRA/INTERPERSONAL LEVEL

Several elements at the individual and interpersonal level were perceived by staff to represent challenges to the systematic implementation of person-centered care. These included staff *attitudes*, *values, motivation* and *knowledge* concerning person-centered care. Indeed, several staff members I interviewed believed that successful implementation of person-centered care was dependent upon staff's commitment to this approach. Whilst individual knowledge and training in person-centered care was certainly recognized as necessary, this was not perceived to be the primary source of concern. Indeed, as one administrator and a care assistant from *Peaceful Gardens* expressed:

> *In all the years that I have been employing people, I have always said that it's very nice to have good skills… one might have done a lot of schooling, and many training course, and what not… but to me, the most important is that one cares about people. That one cares about those with behavioural challenges… that one is interested in physical and cognitive function, and in a way, has an interest in doing that little bit of difference. So, you're not necessarily 'headhunted', but rather 'hearthunted'*

> *I don't think you should have to be told to sit down and listen and be caring? [laughs]… if you're going to be in this line of work, then maybe you should have care for others, that's important… not just be in it for money [laughs]*

As these accounts reflect, being motivated to care for persons with dementia was considered to be an essential starting point for person-centered practices to be adopted. As another administrator stated:

> *[Residents] are very dependent on the fact that the people who come in here want the best for them, and want to take care of them… and have care and love for them. 'Den basic-en'*[12]*, you need to have that. You need to want this. It's not enough to just say "I'm choosing a profession and this is going to go well", you actually need to want it […] We all have a responsibility to… keep ourselves updated. And that should also happen in our free-time, not only via the nursing home. And that can be difficult to understand […] but everyone wants that to happen via the nursing home or the ward. And that's not possible! So we all have a responsibility for updating ourselves, go online, go in and read… we have books here on person-centered care, dementia…*

Hence, several staff believed that there could be no systematic implementation of person-centered care, unless motivation and commitment to participating in its practice was in place. According to these staff members, the ability to motivate, and be motivated, was dependent on whether staff, across all professional roles, had a positive attitude towards person-centered care, and personal qualities and values that were concordant with its principles. One caregiver from *Bay Views* explained it as follows:

> *It's about being that kind of person… who can 'sette seg inn i deres tilværelse' (put yourself in the resident's shoes) and be present, and see how that person is doing. But I don't think all people have it in them… it has a lot to do with how you are as a person […] and you should be 'nærværende'*[13] *and really active in your job… that's also very important. And there are a lot of us who have to… work on that*

The staff's emphasis on the personal qualities of a caregiver is not unexpected, and has been discussed at length in the literature on dementia care. According to many, the quality of care for persons with dementia is highly dependent on a caregivers' way of being. Sandman, Edvardsson, and Winblad (2006, p. 235) for instance, describe dementia care as consisting of two inseparable parts, 'the doing' and 'the being':

> Doing consists of the tasks that are to be performed, for example feeding, showering, changing diapers, and Being consists of the relationship that is formed between the caregiver and the person with dementia […] the subtle qualities of people's way of being when doing what they do are of the utmost importance for the care of patients with dementia.

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[12] In English: 'That basic' – implies a foundation of certain values that need to be present in a caregiver (my transl.)

[13] In English: 'Present' – implies a close and warm presence (my transl.)

This dichotomy between 'doing' and 'being' as outlined by Sandman et al. (2006) emphasises the need for staff and organizations to move beyond task-oriented care, and suggests that the achievement of good dementia care is dependent on staff's individual qualities and attitudes. Kitwood (1997) for instance, describes a good caregiver as a "highly developed person, one who is open, flexible, creative, compassionate, responsive, inwardly at ease" (p. 120). Similarly, in her study on barriers to person-centered care, Hill (2004) found that quality of staff was highly valued by the participants she interviewed. Her findings indicate that while staff recognized the importance of training, "they tended to see personal qualities as the foundation upon which training could build" (p.130). This is not surprising considering that personal qualities are particularly important for the creation of meaningful relationships between carer and residents, which constitutes a central feature of person-centered care (Innes et al., 2006). Similar findings emerged in the present study, where staff highlighted that while training in dementia and person-centered care is essential, the initial focus of the organization should be on finding staff that are suitable to the task of caring and changing attitudes within the caring organization. As one administrator at one of the nursing homes remarked:

> *What I consider to be my most important role is to find good co-workers, find those who really want to do this, who really burn for this. Whether that's nursing students or medical students or whatever… but they have to burn for this, and see the benefits of using oneself in this field*

While drawing suitable people into dementia care represents an already complex task (Kitwood, 1997, pp. 103-132), changing attitudes within the organization, proves even more arduous. Indeed, staffs' sceptical or negative attitudes have been found to represent an important barrier to the implementation of person-centered care in various healthcare contexts (Hill, 2008; Kitwood, 1997; Moore et al., 2017; Naldemirci et al., 2017) and changing attitudes and professional habits has been recognized as extremely difficult to achieve (Brooker & Latham, 2016; Innes, 2009; Kitwood, 1997). According to Kitwood (1997), "it is relatively easy to gain in knowledge and skill, but attitudes are often difficult to change" (p. 112). Accounts collected in this study seem to resonate with these findings. This is how one nurse described it:

> *But it's clear that we are some old idiots, like… I mean, it's difficult to change attitudes, and I think person-centered care has a lot to do with attitude. It very much has to do with attitudes, that's basically what it is. And I think changing that attitude… many [staff] still have this belief that the most important is that residents are clean and nice with no stains on their clothes and showers every Tuesday… very much like that… for many [staff] that's what matters the most […] but I think working on attitudes is… person-centered care is very much about having the right attitude, and changing attitudes is one of the most difficult things to accomplish […] It's*

> *not actually bad that some of us are like that… but it's also… I mean, I think it's worse with those who are like "åh puttenutte, sett deg her nå puttenutte"... that infantilizing, you know? Like "kom her da vennen min"*[14] *it's like "grr" [sound of frustration]*

While another co-worker from the administration, explained that the way in which dementia and dementia care used to be taught may have contributed to some staff having a sceptical attitude towards person-centered care:

> *I think it's a challenge for individual persons because we are… old-fashioned care assistants for instance. […] we were very concerned with patients getting up, sitting nicely in the living room or in the hallway, newly combed and clean, right? It was supposed to be free of any dust, and tidy, and that was in a way… It was very task-oriented. That's what was important. You got praise from the head nurse when the room was spotless, 'du kunne sprette femmer'n på lakene omtrent'*[15]*. Those were the things that were given attention. While staff who oriented themselves towards the residents, and sat and chatted with them all day, they were frowned upon right? Because they weren't doing what they were supposed to do… so of course… like here for instance, we have people who have worked here many years, and so I think that they also have these barriers within themselves. We all of a sudden are supposed to start working in a different way, that is a little less definable… and I think it's also about… being able to acknowledge that skill that comes from being who you are. Right? […] To be able to acknowledge that we have personal qualities that can be used professionally*

Although the debate surrounding the "old culture of care" (Kitwood, 1997) and its transformation towards a new, more humanizing, care practice has been going on for decades, these accounts are reflective of a tendency for inappropriate and task-oriented care practices to persist within dementia care. According to Kitwood, such values and practices that are concordant with the old ways of caring need to be recognized and "unlearned", in order for a new way of caring to be adopted (Kitwood, 1997, p. 113). This issue was also raised by Naldemirci et al. (2017) who identified force of habit and the risk of falling back to well-known routines, as barriers to implementing new practices of care. Brooker and Latham (2016) argue that habitual practices over an extended period of time become normalized to the point that they are carried out unthinkingly. According to them, "old habits are hard to break precisely because people do not recognize them as habits" (p. 30). It is not surprising then, that the attitudes and practices of some staff, as described in the accounts above, reflect a tendency to perpetuate the "old culture of care". Furthermore, other accounts reveal the stronghold that such a care culture has on other staff members, especially those in lower paying roles. For instance, one care

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[14] Both connote use of demeaning terms of endearment

[15] In English: "You could bounce a coin on the sheets" (my transl.) – implying something that is very neat and tidy

assistant at *Peaceful Gardens* explained that she changed the way she prioritized and carried out her daily tasks depending on who she was working with:

> *If I know that the person I'm working with that day is very concerned with practical things… like the laundry room should perfect, and the kitchen should be perfect and the dinner should be served at exactly 4pm [knocks on the table]… then I adjust… so instead of maybe letting a resident put on their socks on their own, I take over unfortunately [knocks on the table]*

My findings reveal that the nature of both individual attitudes and interpersonal relations between staff may, at times, represent a source of challenge for the adoption and practice of person-centered principles. This is in concordance with other findings that recognize individual and interpersonal forces in the care environment as important aspects of the delivery of person-centered care (Brooker & Latham, 2016; Hunter et al., 2016; Kitwood, 1997; McCormack & McCance, 2010). However, although individual and interpersonal factors have been identified as barriers to person-centered care, the extent to which these factors (compared to other identified barriers) influence the implementation of person-centered care remains to be established (Hunter et al., 2016).

Another issue brought forth in the interviews was the level and gap in staff understanding of person-centered care. Chapter Three showed that although staff had an overall awareness and understanding of person-centered care principles, their individual understanding was not always complete, with staff members emphasising some aspects of person-centered care, while leaving out others. Naturally, this differential understanding in itself poses a challenge to the systematic implementation of person-centered care across the dementia care wards. As one administrator explained:

> *The challenge is that the understanding differs… and that's really the biggest challenge… because I feel that the team supervisors are very, very skilled… but the challenge is that there is no tradition for talking about it [person-centered care] […] but if you work in an environment where there is a high level of competency, as there is here, then what makes it even better is to have those who are here to be good role models, and get them to speak the same language. Speak dementia care, talk about what makes that difference, be able to explain why we do, why we say and why we think certain things. And that's a focus that I have now too, how to be that good role model… what are you doing? and what are you not doing? And what could you do more of?… To get that common understanding*

Several qualitative studies from the UK, Ireland, Sweden and Canada have looked at staff understanding of person-centered care and its implication for practice change (Colomer & de Vries, 2016; Hunter et al., 2016; Naldemirci et al., 2017; Talbot & Brewer, 2016). A study of two nursing homes in Ireland found that varying levels of care assistant's training and knowledge of person-centered care partly contributed to the lack of person-centered care implementation in practice (Colomer & de Vries, 2016). In addition, the lack of coherence in terms of how person-centered care is defined and viewed by professionals has been identified as an important challenge to the proper adoption of person-centered care in practice (Naldemirci et al., 2017).

Moreover, the findings from this study suggests a tendency for differential understandings of person-centered care to result in a differential perception of implementation challenges. For instance, although the factors discussed in this section were certainly perceived as a source of challenge by many, it was mostly raised by those who emphasized person-centered care as a set of values and way of being. Others, who perceived person-centered care as synonymous to individualized care, believed that the core of difficulties, laid not with individual or interpersonal factors, but rather was a result of challenges at a higher level, pertaining to organisational factors such as time and staffing constraints. The following excerpt from an interview with a nurse emphasises the divide in perceived challenges:

> *It almost makes me noxious that whole discussion about us not having enough time and staff, because it's been that way for years, but sooner or later you should learn how to navigate that I think. We'll never get enough time, but then again acknowledging a resident, saying hello and looking them in the eyes, that doesn't take any time […] I mean of course, if we had 30 more staff on call everyday… but no, I mean, maybe it's wrong of me to say that, but I don't think it's a matter of time… it's really not. Because we'll never get more time. It's about how we choose to use that time, that's the issue, that's what we should focus on. We can choose to use our time on complaining about having to prepare dinner, right? Or discussing how unfair it is that we have to prepare dinner… that's easily 30 minutes gone by [laughs] […] but that's… well I've become indoctrinated so… but that whole talk about us not having time, that's simply not right… because saying "hello" doesn't require any time… I think person-centered care is about behaving properly, and acknowledging people as people, that's what it is! That doesn't take any time, maybe it can even save you some time*

To my knowledge, there are no studies that have delved into the relationship between how person-centered care is defined and the nature of perceived implementation challenges, and as such, this is a finding that may warrant further exploration. Yet, while some staff members at both *Peaceful Gardens* and *Bay Views* were convinced the challenges they encountered were tide to professional attitudes and values, others rejected this idea, putting forth organisational factors as another explanation for the on-going task-oriented practices and the lack of care practice change in their wards.

4.2 CHALLENGES AT THE ORGANIZATIONAL LEVEL

According to McCormack (2004), "the context in which care is provided has the greatest potential to enhance or limit the facilitation of person-centered practice" (p. 34). Hence, although individual care values are certainly important to consider, there is a need to recognize the strong impact that organizational demands have on the implementation of new practices of care (Brooker & Latham, 2016; McCormack, 2004). A review of the literature on person-centered care implementation reveals major organisational barriers to the proper delivery of person-centered care, including, but no limited to: Adherence to routines and inappropriate care priorities (Edvardsson et al., 2008; Hill, 2008; Hunter et al., 2016); recruitment and high staff turnover (Brooker & Latham, 2016; Innes et al., 2006); inappropriate staff-resident ratio (Colomer & de Vries, 2016; Talbot & Brewer, 2016); lack of training and education on person-centered care (Colomer & de Vries, 2016; Harding et al., 2015); and unsupportive leadership (Brooker & Latham, 2016; Innes et al., 2006; Rokstad et al., 2015). Findings from the present study reveal that although *Peaceful Gardens* and *Bay Views* were organized differently, staff from both institutions reported similar issues in terms of the challenges they encountered at the organizational level, which, in their view, made everyday practices of person-centered care difficult to achieve. In particular, these challenges included *lack of appropriate resources,* such as *time constraints* and *staffing constraints*, which according to many staff members, translated into a heavy workload and task-oriented care. Moreover, *insufficient training opportunities* was also recognized as a potential challenge to the proper implementation of person-centered care.

Undeniably, some of these reported challenges are a direct consequence of the larger political and economic context within which nursing home organizations are located. This is partly what Brooker and Latham (2016) refer to in their discussion on the importance of being able to mediate "external factors" to protect front-line care delivery (p. 44). The authors define external factors as "anything from outside of the organization or specific workplace that can have an impact on the day-to-day practice of staff and thus the support of people living with dementia" (p. 44). As such, external factors include, but are not limited to: financial and resource decisions, policies, frameworks and quality requirements (Brooker & Latham, 2016; Innes, 2009) that may have a direct influence on how care is organised and delivered at the organizational level. Nonetheless, Brooker and Latham (2016) argue that it is the way in which the organization, particularly management, mediates the effects of external factors, rather than the factors themselves, that determine their level of impact on person-centered care provision.

4.2.1 Lack of appropriate resources

The issue of inappropriate resources and staffing levels, and the time constraints that ensue, is not recent, nor unique. Over 20 years ago, Kitwood (1997, p. 103) eluded to this matter in his writings:

> The organization has to find a way to set each person free to do his or her best work, while also safeguarding against slovenliness and inconsistency; there are standards to be maintained. An optimum solution has to be found, and in a general economic context of limited resources.

Undoubtedly, these issues are still true today. Indeed, several studies on dementia care point to the tensions that arise between organisational demands and care demands within a particular care setting (Hill, 2008; Innes, 2009; Moore et al., 2017). Also in qualitative studies focusing on care professionals' experiences of dementia care, we find that staffing levels, inadequate staff-resident ratio and time pressure run as common themes, and are often reported as some of the reasons for suboptimal and task-oriented care to persist in long-term care (Colomer & de Vries, 2016; Hunter et al., 2016; Smythe et al., 2015; Talbot & Brewer, 2016). Kleiven, Kyte, and Kvigne (2016) focus group study which included nurses from community health services and specialist services indicate that these issues are not confined to dementia care, but rather shared by most, if not all, health care services. Their findings also suggest that in care that focuses on psychosocial needs, activity and relationality is the first to be neglected by staff in a busy work environment.

In relation to the present study, the problem with a buys work environment driven by routines and practical tasks is two-fold. Firstly, a rigid schedule is essentially incompatible with the flexibility and creativity that a person-centered approach requires (Hunter et al., 2016; Innes, 2009; Kitwood, 1997; Talbot & Brewer, 2016). As one of the nurses from *Peaceful Gardens* noted, "if we prioritize the practical things, the resident is forgotten… and so many of us, we complain about that… that we don't have enough time for the residents". Secondly, and even more frequently reported in the interviews, is the effect that routine tasks had on staff's well-being and feelings of internal coherence. Indeed, several staff members from both institutions reported feeling conflicted in their role as carers, not knowing how, or what, to prioritize. An excerpt from an interview with a care assistant highlights this point:

> *They should feel safe, and heard, and have ownership over their everyday lives, as much as possible… it's not my place to say "now you need to go to the bathroom! No you don't need to go to the bathroom!" … but we also don't have enough time… so it's a little bit like… "what*

> *should I do now?" when it's 9pm and I have to start writing my report! Do I follow her (resident) to her room right away? No, but she's sitting in the living room, what do I do? So it's a little bit like… [exhales deeply] Usually I have to try to get her to go to bed because I have to go home at 9:45pm [laughs] and I have to think about the one who's coming to work the nightshift… that person is not going to start her shift and have 5 residents still sitting in the living room, and have to put everyone to bed by herself because they didn't want to go to sleep… because that's person-centered care…"no they didn't want to", well yes, but how is the person working nights going to handle 14 residents on their own? […] So it's a little bit like balancing on a tightrope […] I feel like I always have to balance… like "what am I going to do now for everyone to be happy?" […] It's like I told you… and now I have to speak from my own experience… I feel like I constantly have to choose… I have to choose… I work daily with prioritizing… should I write 10 bullet points on a report or should I be with this resident? So, I have to prioritize… so there's a lot of "what should I do now?"*

This notion of conflict between practical tasks and person-centered 'tasks', was echoed in several interviews, especially by care assistants or ward nurses working on the ground. Their feelings of conflict were, at times, exacerbated by what they perceived as 'extra' tasks, imposed on them by the administration. These 'extra' tasks included practical tasks that, in their view, fell outside the scope of their professional role. As one nurse expressed:

> *There should be at least one of us in the common room [with the residents], at all times of course. But there are other things that need to be done too… so what should we prioritize? So sometimes, it's like… should I be here? Or should I go there? And things, things don't get done, people get frustrated because it doesn't get done and… yes things like that, small things. But it's those practical things… doing laundry and other things, that fell on us… extra tasks.*

In their study of care assistants' experiences in long-term dementia care, Talbot and Brewer (2016) report similar findings, whereby care staff experienced feelings of role conflict as a result of demands in the work environment being at odds with their caregiving role. Moreover, Talbot and Brewer's study revealed that approaches to care remained task-oriented even in situations when staff had adequate time to spend with residents. According to the staff the authors interviewed, this was an effect of "organisations giving staff 'extra jobs' to do when units were quiet" (p. 1747). In the present study however, the debate surrounding 'extra' tasks revealed an underlying conflict between management's and ground staff's perception of how to operationalize good dementia care. Whilst several staff, working directly with residents, perceived these tasks as an unnecessary addition to their workload, the administration, on the other hand, defended these tasks as a way to operationalize principles of person-centered care in practice. At *Peaceful Gardens* for instance, the primary vision was to make every ward feel like home, in an attempt to normalize resident's stay in the nursing home. Introducing tasks in which residents could participate, such as making dinner, folding laundry etc. was therefore a concrete strategy to uphold residents' sense of personhood. As one administrator argued:

> *We will never have enough people to the point that everyone says "no, we're enough". And I think that as long as we…for instance, in relation to how we organize tasks in the ward… as long as we continue in the same tradition as we have before, then it's like we work in the same way we used to work and **in addition** we have to do something new. Right? **In addition**, we have to make food, **in addition**, we have to do the laundry, and be with the residents. Instead of bringing the resident with you throughout the day, right? And include them in the tasks around the ward… I mean that we'll never have enough [staff], we won't get any more [staff], but I think we have a lot to learn about how we organize ourselves…*

However, when asked about the institution's vision of care, one care assistant replied:

> *They say that they want everything to be like 'home', where you make dinner and do laundry […] but it breaks us… if you have to clean and make food, then you need some more staff as well… you can't expect us to wash clothes, bring clothes to the rooms, cook, go grocery shopping, when there's only two of us here*

Similar findings emerge from Smythe et al. (2015) study on the experiences of staff providing dementia care within a specialist mental service, in which they found that participants perceived person-centered care as a completely separate and additional task, rather than an approach to care that could readily be incorporated into their day-to-day activities. Smythe et al. (2015) findings strongly support Talbot and Brewer (2016) suggestion that "organisational definitions of care clash with care assistants definitions of quality care in the dementia environment" (p. 1747). Much of the literature on the implementation of person-centered care has already pointed to the need for organisations to assess the degree to which staffing levels, task allocation and time availability, impede on person-centered care practices (Brooker & Latham, 2016; Hill, 2008; Smythe et al., 2015). While it seems particularly urgent to address the conflict between organizational demands and care demands, the present findings suggest a need to further explore and address the tension arising between the administrations' implementation strategies grounded in theory and frontline workers reality of dementia care on the ground.

4.2.2 Insufficient training opportunities

> *But it's like I said, once you actually go to school, you go from doing something because you see someone else doing it, to doing something because you understand the professional value of it. Because there are a lot of things we all do here, whether you're an assistant or a nurse… we do a lot of things umm because we do it, because it's become routine… so we do it, but we have no scientific evidence for why we are doing it. We don't question it.*

This passage, which was taken from an interview with a care assistant working at *Peaceful Gardens*, represents a good starting point for the present discussion on dementia care training. In particular, the passage underlines the importance of knowledge and education, in order for staff to be able to understand the rationale behind the adoption of person-centered care principles. As such, making sense of person-centered approaches from a theoretical perspective was considered as important for breaking with the automated task-oriented practices of care.

During my time in the field, *Peaceful Gardens* was just in the first stages of VIPS training, which was organized internally, with VIPS seminars led by one of the head nurses. Due to organizational aspects, not all staff members were able to attend the training, but a few staff members from each ward were picked out to attend. Training staff in VIPS was an effort to systematize person-centered care practices in the institution. The training also allowed for staff members who had limited knowledge of person-centered care to get better acquainted with this approach. Some staff members had also attended external training courses in dementia care. *Bay Views* on the other hand, had previously organized a few internal seminars focusing on person-centered care and VIPS, and similarly to *Peaceful Gardens* had sent some of its staff to external training courses in dementia care. Both institutions also organized lunch seminars or informal meetings to discuss any relevant topics concerning the work environment, dementia care, person-centered care or any issues they encountered during their shift. Finally, both organizations had sent some of its staff and/or administrators on a work trip to The Hogeweyk, a dementia village in the Netherlands recognized internationally for the quality of care it provides. Despite the organizations' attempts at increasing staff's level of knowledge on dementia and person-centered care, the people I interviewed raised concerns related to the limited training opportunities, the relevance of knowledge gained through such training, and the unsystematic way in which training opportunities were offered to staff.

Both staff who had attended training seminars and those who had not, expressed the need for additional training opportunities. One care assistant from *Peaceful Gardens* told me that "These past few years, there's been almost no courses… it's been pretty bad with courses actually. I really miss getting some refresher courses" while another care assistant from *Bay Views* explained:

> *There was a period when I attended a lot of courses… especially during the first years. I was often attending courses and the institution were very committed to training […] I took the 'Demens i hverdagen'*[16] *course which was a very extensive course. And now there's been a few*

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[16] In English: 'Dementia in everyday life' (my transl.)

> *years with almost no courses. And so, I think… there's a lot of new staff here, who haven't worked here so long, and I don't know what kind of courses they've taken, but I don't think they've been to many*

Moreover, staff members from both *Bay Views* and *Peaceful Gardens* who had previously attended training courses on dementia care and/or person-centered care, had divergent views on whether this training was actually relevant and helpful. One care assistant from *Peaceful Gardens* said:

> *It's interesting to sit there and listen but it's like... theoretically, there's so much good stuff, but it doesn't always work in practice… because here we have a little more to take care of than just one person [laughs] because usually, when you attend these courses they envisage only one person, right? But here we're like two carers for seven residents.*

While a care assistant from *Bay Views* expressed it as such:

> *No… courses… I don't really see how courses help. You forget after a while, because you don't use it. When we work here… if everyone who worked here took the initiative to use that knowledge then yes, it would help. Because then we are helping each other and reminding each other of things, and in the end, we can see that the seed we planted is growing. But if you only attend one course and use it 2, 3, days… then it doesn't help at all.*

The issues presented above echo with findings from previous studies on training of care staff and its implications for the implementation of person-centered care. In a qualitative study on person-centered dementia care in Ireland mentioned earlier, Colomer and de Vries (2016) found in their interviews, that care assistants' lack of knowledge and training in person-centered care prevented the interviewers from being able to "delve more deeply into PCC" (p. 1162). Even though participants they interviewed worked for nursing homes with a person-centered care policy, the majority reported not having received any specific training in person-centered care, including a few who had never heard of person-centered care. As a result, much of the care provided was limited to task-based approaches, which stood in stark contrast to what the institutions were promoting.

According to many staff members I interviewed, the way person-centered care is taught is not applicable in practice, because it does not take into consideration the reality of their work environment. In their study on care assistants' experiences of dementia care, Talbot and Brewer's (2016) report that the staff they interviewed expressed a desire for dementia specific training, in order to improve the quality of care provided. However, similar to the findings in my study, participants in Talbot and Brewer's (2016) study also displayed conflicting views regarding the usefulness of dementia training, citing the need for training programs to be reflective of “real life” dementia care environments (p. 1748). Moreover, Smythe et al. (2015) study on the experiences of staff working in specialist mental health services, found that classroom-based learning of person-centered care was viewed as unnecessary, as participants felt it was as “out of touch” with the “real world” (p. 192). These findings are important, because they seem to encapsulate one reason for the gap that currently exists between theory and practice. With regards to the difficulties of implementing training into actual practice, Innes (2009, p. 95) argues that “any ideology or approach embraced by management needs to be translated into care strategies that those at the frontline of care delivery can adapt and work with in their existing work cultures”.

Another issue raised regarding education and training, was the unsystematic way in which it was offered to staff. With regards to unequal training opportunities, two main points should be made. Firstly, the interviews reveal that while some staff had attended several courses or seminars regarding dementia, dementia care and/or person-centered care, others working within the same wards had not had the same opportunity. Interviews revealed that some staff working within the dementia wards were lacking basic knowledge on dementia and dementia care. One care assistant from *Bay Views* for instance, expressed unease regarding the perceived low level of knowledge of some of her co-workers:

> *You need to have knowledge of the diagnosis. There are maybe many here who don’t know… what is anxiety? What is dementia? Why do they behave a certain way? Why do they hit? And I feel bad when there are young carers who come here and don’t know anything. No… the thing about knowledge… you actually have to… learn. Because if you don’t know anything, then it doesn’t work. If you don’t know how should behave towards a resident… and the residents, most of all, they notice that you’re not present, that you don’t know.*

Secondly, there is an increasing number of training courses and programmes available for dementia care, each with a different duration, area of focus and level of emphasis on person-centered care. Hence, this variability in training intensity and content resulted in unsystematic competence even for those staff members who had had the opportunity to attend courses. This certainly impeded on the systematic use of person-centered practices in the wards, and moreover, created conflict between co-workers who had differing knowledge of dementia and person-centered care:

> *I’m frustrated because I want to do more for the resident but I have other tasks I have to do too. I have to take care of the laundry room, and other tings too! And others in the staff are so concerned with these practical tasks but if we all had more knowledge, it would be easier. Because then they would have understood me better… “oh you spent 40 minutes on one resident!”… Yes, well if you had the same educational background as me…*

More evidence is needed with regards to how training programmes should be applied and, in particular, what type of training programmes and manuals show evidence of efficacy for the implementation of person-centered care (Fossey et al., 2014; Hunter et al., 2016). Following the launch of the Norwegian Dementia plan 2015 (Norwegian Ministry of Health and Care Services, 2008), the Norwegian Advisory Unit on Ageing and Health developed the *Demensomsorgens ABC* educational programme, with the aim to systematically increase competence in dementia care and person-centered care (Rokstad et al., 2017). A longitudinal survey evaluating the educational program and its impact on person-centred care competence, found that the training did have a positive impact on self-reported person-centeredness in staff who had completed the training (Rokstad et al., 2017). However, the study did not evaluate whether the self-reported increase in person-centeredness actually led to positive changes in care practice. A review by McCabe, Davison, and George (2007) focusing on training programs that address behavioural problems associated with dementia, note that the heterogeneous content and variability in intensity and length of staff training programs makes it difficult to draw conclusions about their effectiveness. Moreover, a meta-analysis by Fossey et al. (2014) on the quality and efficacy of person-centered care training programs found that only 18% of the identified training manuals met their quality criteria for good educational and person-centered care principles. Fossey et al. (2014) also reported that 98% of the existing training manuals identified in their study were not evidence-based. These findings highlight the need for administrators and management to assess the quality and efficacy of training programs that are available to them (Fossey et al., 2014; Griffiths, Surr, Creese, Garrod, & Chenoweth, 2018).

Above all, the question remains whether training itself is enough to bring about long-term changes in practice. Citing Fook and Gardner (2007), Smythe et al. (2015) note that "being exposed to, or knowing, a theory does not necessarily mean that it is integrated into functioning and action" (p. 194). Similarly, Hunter et al. (2016) argue that it is still uncertain "whether changes in knowledge translate to changes in practice" (p. 1214). Indeed, several studies point to the fact that although certain training programmes facilitate changes in practice, these changes are often short-lived, rather than sustained over time (Fossey et al., 2014; Hunter et al., 2016; McCabe et al., 2007; Naldemirci et al., 2017; Smythe et al., 2015). Hence, it has been suggested that several elements need to be in place for training interventions to be successful in bringing about sustained change. These elements include, but are not limited to: Organisational support (Rokstad et al., 2017; Smythe et al., 2015; Talbot & Brewer, 2016); group training and reflection sessions within the organisation (Colomer & de Vries, 2016; Smythe et al., 2015) and; appropriate working conditions (Innes, 2009; Smythe et al., 2015).

4.3 CHALLENGES AT THE NATIONAL LEVEL

As previously mentioned, nursing homes are prone to external sources of pressure that will have differing implications for the implementation of person-centered care (Brooker & Latham, 2016; Innes, 2009). While some of these sources of pressures have already been discussed in the previous section, there is a need to address the ways in which the overall management structure of the health care sector in Norway affects the delivery of quality care in nursing homes. Staff I interviewed often referred to “the politicians/politics”, “the system” and “the economy” when addressing what they perceived to be the main challenges, or limitations, to the implementation of person-centered care in their organization. Some staff for instance, pointed to the overarching political frameworks within which they worked, as this nurse and administrator from *Peaceful Gardens*:

> *It’s a challenge when we’re working so close to the political level. We’re so dependent on what politicians who are in power actually think. Because they just say “now, this is what matters” and we have to follow that. So it’s a challenge… to get that common political vision of how the care sector should be.*
>
> *But I think… right now, there are managers and politicians sitting in their offices, basking in their glory, thinking “we’re doing this so well” right? But in reality, it’s not… but I think we’re getting there… yes I think so.*

Others again emphasised the economic context as potentially shaping the caring practices. Here are some excerpts by a care assistant and an administrator, that reflect some of the main points that were made in this regard:

> *I think it has a little to do with economy. And economy is sort of the enemy of person-centered care I would say. Because often… it’s the economic focus that leads us to having to do as much as possible with the least amount of people.*
>
> *To work on those care relationships… to be able to work closely with the residents and have continuity in the care we deliver, that’s so important. So that’s always one of my concerns when there’s talk about resources and budget allocations and frameworks and such… if we need to do any budget cuts. Because I see that a lot of the foundation for doing a good job is to have the opportunity to have a good relationship [with the resident].*

The past few decades have seen marked changes in how Norway’s public sector is governed and organised, particularly with the introduction of a series of reforms underpinned by New Public Management (NPM) strategies (Kleiven et al., 2016; Kristiansen, Westeren, Obstfelder, & Lotherington, 2016; Neby, 2016; Tingvoll, Sæterstrand, & McClusky, 2016). NPM is described as a process that transformed the relationship between the private and the public sector, whereby "citizens and clients were recast as consumers, and public service organizations were recast in the image of the business world" (J. Newman, 2000, p. 45). With regards to the health care sector in Norway, the introduction of NPM-inspired reforms has resulted in a management style characterized by measurement, reporting and controlling of target objectives and performance indicators with the aim to increase efficiency, productivity and quality of services (Kleiven et al., 2016; Neby, 2016). A body of literature focusing on the impact of NPM-inspired health care reforms point to the adverse effects of this model on nursing and nursing care in various health services (Kleiven et al., 2016; Kristiansen et al., 2016; S. Newman & Lawler, 2009; Tingvoll et al., 2016). In their study exploring the challenges faced by primary health care nurse leaders in Norway, Tingvoll et al. (2016, p. 1) write that "Whereas the NPM model may be readily applied to the governing of other public services, the model's suitability for the administration of nursing and healthcare that, in essence, entails a round-the-clock service for patients, […] is less than ideal".

Other European and Western countries have undergone New Public Management reforms. Australia's public health care system for instance, underwent a series of NPM-inspired reforms in the 1980s. S. Newman and Lawler (2009) explored the reformed health care environment in Australia as experienced by nurses, and aspects of their findings seems to resonate with some of the notions expressed by staff at both *Bay Views* and *Peaceful Gardens*. S. Newman and Lawler (2009) write:

> The productivity focus – 'do more with less' (Cordery, 1995) – has affected nursing's potential to deliver care. Nurse managers are expected to motivate staff and promote cultural change, but are hard-pressed to do so in a downsized environment characterized by increased intensity of both managerial and clinical nursing work and the weakened tenure of management positions. All these contradictions are framed by increasing political interference (Pollitt and Bouckaert, 2004) (p. 429).

In the health care context, NPM-inspired changes translate into an increased need for documentation and reporting, meeting performance indicators and prioritizing target objectives that are measurable (Kirkevold, Holter, & Burås-Leine, 2013; Kristoffersen & Friberg, 2016; S. Newman & Lawler, 2009), the immediate result of which is the neglect of those aspects of care that cannot be measured, such as the quality of a resident-caregiver interaction or the meeting of psychosocial needs (Hill, 2004; Kleiven et al., 2016) – care principles that are inextricably linked to person-centered care. The situation at *Bay Views* and *Peaceful Gardens* is no exception. Here's an excerpt taken from an interview with an administrator:

> *Firstly, I think that the health care sector is so driven by tradition, which makes it more difficult in this sector to make changes than in others […] the management system we have in the health sector is so much more rigid than in Forsvaret!*[17]*. And that says something about commando lines and lines of responsibility and it's… it's really kind of insane […] So I think that… the tradition isn't really on our side […] and there's a few elements in this approach [person-centered care] that doesn't really fit with that målstyringstradisjonen*[18] *that we currently have, right? Person-centered care is hard to go in and control, and measure, and… so I don't think it would be so bad, if we were able to put away that mentality. I mean, I think that management by objectives, very often leads the controlling level… the higher level, to control… the wrong things. In a way, they control at such a level of detail, that it's complete nonsense. I believe we should get better at using people for what they actually are here to do, and in order to do that, we have to let go a bit. Because as long as they continue managing by objectives like they do now, we'll always experience conflict between what we wish to do and what we actually manage to do […] it's difficult to transfer that way of thinking to our caring profession. Because staff is, in a way, driven into a framework that they need to achieve because that's what they are controlled on […] for instance in home care, where they're not even able to serve a cup of coffee because it says in the decision plan that they're there to change a wound dressing. That's new public management…*

The article entitled "Gjenreis helsefagenes verdigrunnlag!"[19] by Kirkevold et al. (2013) takes a firm stance against the New Public Management ideology governing the health care sector in Norway. The article describes a work environment comprised of increased control and excessive bureaucratization, where care for the individual is no longer the main focus. Moreover, Findings from Kleiven et al. (2016) paint a picture of a work environment where nurses often experience that they have to go against their professional ideals and values. According to Kleiven et al. (2016) the introduction of NPM-inspired management frameworks in the Norwegian health care sector creates a condition whereby fundamental values in nursing such as care, respect and dignity are given less space. In their view, when priority is given to target objectives that can be controlled and measured, the nurses' professional focus shifts away from being patient-centered, to becoming increasingly task-centered. I believe that this is an important point with regards to person-centered care – an approach that values the quality of caregiving relationships, rather than quantifiable and measurable tasks. To the best of my knowledge, no study in Norway has explored the health care sector management and its impact on dementia care practice in nursing homes. However, in her study on barriers to person-centered care in an Australian nursing home, Hill (2004) argues that: "the marketplace ideology reinforces the focus on physical (and measurable) care, which puts great pressure on institutions

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[17] In English: Norwegian Armed Forces

[18] In English: "Tradition of management by objectives" (my transl.)

[19] In English: "Revive the value base of the health sciences!" (my transl.)

and staff who try to offer care which is based on relationship" (p. 242). Similarly, in their study on person-centered dementia care in Canada, Kontos and Naglie (2007) note:

> The rationale of economic efficiency creates a system wherein the measure of care lies with the physical task rather than the quality of human interaction and, as a consequence, the relationship between the care provider and recipient is not quintessentially one of caring (p. 550)

Several staff members at *Bay Views* and *Peaceful Gardens*, especially those in administrative positions who were trained nurses, reported increased pressure to deliver on key performance indicators and target objectives that were not always consistent with their professional care ideals. The pressure was also felt by front-line staff, who pointed to an increased emphasis on reporting and documentation, at the expense of time spent with residents. One care assistant best summarized it as: "Those who are highest up in the system, they put pressure on those below, who then put pressure on us".

4.4 CONCLUSION: translating theory into institutional practice

This chapter delved into the difficulties experienced by staff in their attempt to systematically implement person-centered care into institutional practice. Findings revealed that the challenges they identified pertained to multiple levels of influence, and that furthermore, these perceived challenges were to some extent guided by the nature of their professional role and their understanding of person-centered care. For instance, if someone's person-centered care ideal was to be able to have long one-to-one contact with residents and individualized activities then challenges were perceived as mostly stemming from a lack of time and staff resources. On the other hand, if person-centered care was understood as a way of being and a value-base for all aspects of the caring relationship, then the challenges were perceived as being mostly related to individual factors, such as the values of individual staff members, the quality of their knowledge of dementia, or their motivation and attitudes towards residents with dementia. Additionally, the discussion uncovered a certain tension between staff in administrative positions and front-line staff, particularly with regards to the issue of time, tasks and resources. For instance, whilst cooking and doing the laundry were at time perceived by front-line staff as 'extra' tasks with no relevance to their role as carers, staff in administrative positions explained that these tasks did in fact have a therapeutic purpose in the sense that it gave residents a chance to engage in activities that were familiar to them. It also contributed to a less institutionalised and more home-like environment, which was an area of focus for both dementia plans 2015 and 2020 (Norwegian Ministry of Health and Care Services, 2008, 2015). It therefore seems important for the process of new practice implementation to address the relationship between those who deliver care and those who manage care and align the differing visions of person-centered care existing within the same institutional setting.

The main areas of concern identified by staff pertained to individual staff qualities, such as values, attitude and motivation, lack of organizational resources and relevant training opportunities, as well as regulatory challenges at the national level. Institutions such as *Bay Views* and *Peaceful Gardens* operate within an economic context, which certainly has implications for the provision of care services Additionally, as Innes (2009, p. 92) notes:

> The micro culture of an individual care setting is of course located within a society where there is knowledge about dementia and dementia care, and policy and practice frameworks guiding what is deemed to be acceptable or good standards of care provisions.

Indeed, the present chapter reveals a care staff in constant interaction and negotiation with the larger system within which they work. In particular, the findings highlight that the implementation of person-centered care must be considered in light of the complex array of challenges present within and outside the care environment. It seems that person-centered care cannot be truly implemented within institutions unless careful consideration is given to the interplay between the various levels of influence presented in this chapter, and, while the degree to which each reported challenge actually impacts the implementation process remains unclear, Kontos and Naglie (2007, pp. 550-551) provide some insights that seem relevant to the findings in this study:

> While the consequences of inadequate staffing are not to be disputed, there are factors in addition to staffing ratios that influence the quality of care provided [...] Although more staff can be crucial to providing quality care, increasing staff alone will not resolve the deficit in the quality of care if the additional staff are providing depersonalizing care.

This chapter served to further explore the gap that exists between the theoretical ideal and the reality of practice of person-centered care by highlighting some of the potential reasons for the lack of systematic and all-encompassing implementation of person-centered care at *Bay Views* and *Peaceful Gardens*. The next, and final, chapter will bring together the most important findings from this study in a wider discussion of the current state of dementia care in Norway.

CHAPTER FIVE:

- ENDING REMARKS -

> It is conceivable that most of the advances that have been made in recent years might be obliterated, and that the state of affairs in 2010 might be as bad as it was in 1970, except that it would be varnished by eloquent mission statements, and masked by fine buildings and glossy brochures (Kitwood, 1997, p. 133).

The above excerpt was written by Kitwood more than 20 years ago, and at this moment in time one could be inclined to ask whether Kitwood's speculations proved to be true. While I would argue that considerable improvements and changes have been made in the field of dementia care since Kitwood's writings, a lack of uniformity in the quality of dementia care provision is still apparent. The present thesis set out to gain insight into the gap between person-centered care theory and practice by exploring how staff understood, enacted, utilized and/or resisted person-centered care in the daily context of dementia care in two Norwegian nursing homes. As such, this study uncovered findings related to staff's understanding and knowledge of person-centered care, the ways in which their understanding was translated into individual practice, but also what challenges they encountered in the implementation of person-centered care. The interviews, along with observations, reveals that there are a number of issues that still need to be addressed in order for a person-centered care vision to be truly and systematically implemented in the nursing homes. Specifically, there were gaps in terms of 1) person-centered care theory and staff knowledge of this theory; 2) knowledge of person-centered care and applications of this knowledge in practice; gaps that need to be addressed and reconciled if the care ideals and expectations advocated by *Bay Views* and *Peaceful Gardens* are to become the norm throughout those institutions.

Firstly, as discussed in Chapter Three, staff's knowledge of person-centered care could be summarized into two main points: unevenly distributed and intuitive. In other words, some staff members, especially those in administrative positions had a good grasp of what person-centered care entailed, while others, were either unfamiliar with the term or lacking in their training and/or understanding. However, as Chapter Three also showed, staff's intuitive description of good care and/or person-centered care and the strategies used to translate this knowledge into practice did align with the values and core principles commonly found in the person-centered care literature. So, while individually staff tended to emphasize and embody certain aspects of person-centered care over others, collectively, the themes conveyed through the interviews were reflective of a holistic person-centered perspective. Staff emphasized the need to see their residents, know their residents and empower their residents, care principles that could be promoted through strategies such as: reframing dementia, depathologizing behaviour, using life stories, fostering meaningful relationships, taking the resident's perspective, and encouraging the use of the residents' remaining resources. The fact that even staff members who had no explicit knowledge or training were able to use person-centered care principles by intuition, also points to the very nature of person-centered care as an approach rooted in universally held values of care, dignity and respect.

Secondly, as Chapter Three and Chapter Four outline, having knowledge of person-centered care principles does not necessarily translate into the systematic use of this knowledge in practice. For instance, whilst I was able to capture many meaningful relationships and interactions between caregivers and residents that were consistent with a person-centered care approach, I also witnessed the lack of such interactions on other occasions. As such, the individual practice of person-centered care by a number of dedicated staff members did not significantly translate into a wider institutional practice. This finding could be summed up by Innes (2009) as she relates that: "Person-centred ideals may be implemented some of the time for some of the people, but for some of the time and some of the people they won't be" (p. 48).

According to the findings, many factors seem to influence why person-centered care isn't omnipresent in everyday institutional care practices, and seem to suggest the need for all-around, systemic changes which include: better investment in recruiting the right people for the job; need for systematic training in person-centered care for all staff in order to foster a common terminology and strengthen their knowledge-base; better cooperation and communication between the different professional and bureaucratic levels; better resources; and a management structure which takes into account the reality of staff's work environment, and allows more flexibility in how to best achieve person-centered care. Above all, I argue that the findings presented in this thesis emphasize the existence of relationships, between residents, front-line staff, administrators, institutions and the system as a whole, and the need for these relationships to be taken into account in order to bring about the changes advocated in the mission statements of institutions like *Bay Views* and *Peaceful Gardens*.

In 2008, Moser wrote an article entitled "Making Alzheimer's disease Matter. Enacting, interfering and doing politics of nature" (Moser, 2008), in which she explores the multiplicity of ways in which Alzheimer's disease is shaped and reconceived by drawing on empirical material from a range of locations and practices in Norway. In the article, Moser discusses how different versions of Alzheimer's disease – from the field of biomedicine to that of dementia research and nursing practice – co-exist and, at times, interfere with each other. The article demonstrates the stronghold of biomedical and pharmaceutical versions of Alzheimer's in parliamentary politics, making other care alternatives practically invisible. Moser (2008, p. 107) writes:

> So politics is an important site. It is a location that is supposed to collect, but also to evaluate and regulate what versions of the matter at hand should be included and excluded, and so get a chance or not [...] it is much easier for parliamentary politics to handle, approve of and promise access to medications than it is to promise competent, adapted, long-term care services.

Now, ten years later, alternative representations of what dementia is and how it can be treated has been given space in the political arena. New expectations have emerged in terms of the quality of care services provided to persons with dementia, the way we conceptualize dementia is slowly changing, and the benefits of using psychosocial approaches have been gaining ground. For instance, whilst the Dementia Plan 2015 (Norwegian Ministry of Health and Care Services, 2008) made no overt mention of person-centered care, the description of proper dementia care was rooted in principles and values concordant with a person-centered care perspective. The Dementia Plan 2020 (Norwegian Ministry of Health and Care Services, 2015), which builds on the previous Dementia Plan, acknowledges the impact of the physical and social environment on persons with dementia, and as such, the primary aim of the plan is to develop a more Dementia-friendly society, which requires changes in "societal attitudes, ways of thinking and political priorities" (p. 15). The Dementia Plan 2020 makes a concrete reference to the "person-centred approach" in talking about how health and care services should be designed (p. 18). The plan specifically refers to the need for the services offered to "focus on the person [...] taking account of their world view and enabling them to make use of their resources" (p. 18). Despite these encouraging developments in the field of dementia care, I argue based on my findings and the literature I have consulted in the making of this project, that there is still a gap between theory, policy frameworks and practice in Norway today. It is uncertain whether the care standards espoused by the Dementia Plan will ever become a widespread reality for persons with dementia living in long-term care facilities, unless the reality of those who live and work in these settings is addressed.

REFERENCES

Aggarwal, N., Vass, A., Minardi, H., Ward, R., Garfield, C., & Cybyk, B. (2003). People with dementia and their relatives: personal experiences of Alzheimer's and of the provision of care. *Journal of Psychiatric and Mental Health Nursing, 10*(2), 187-197.

Ballenger, J. F. (2006). The biomedical deconstruction of senility and the persistent stigmatization of old age in the United States. *Thinking about dementia: Culture, loss, and the anthropology of senility*, 106-120.

Barbosa, A., Sousa, L., Nolan, M., & Figueiredo, D. (2015). Effects of person-centered care approaches to dementia care on staff: a systematic review. *American Journal of Alzheimer's Disease & Other Dementias®, 30*(8), 713-722.

Brinkmann, S., & Kvale, S. (2015). *InterViews : learning the craft of qualitative research interviewing* (3rd ed. ed.). Thousand Oaks, California: Sage.

Brooker, D. (2004). What is person-centred care in dementia? *Reviews in clinical gerontology, 13*(3), 215-222.

Brooker, D., & Latham, I. (2016). *Person-centred dementia care : making services better with the VIPS framework*. London and Philadelphia: Jessica Kingsley

Brownie, S., & Nancarrow, S. (2013). Effects of person-centered care on residents and staff in aged-care facilities: a systematic review. *Clinical interventions in Aging, 8*, 1-10.

Buber, M., & Smith, R. G. (1937). *Ich und Du. I and Thou... Translated by Ronald Gregor Smith*: Edinburgh: T. & T. Clark.

Castillo, E. H. (2011). Doing dementia better: anthropological insights. *Clin Geriatr Med, 27*(2), 273-289. doi:10.1016/j.cger.2011.02.002

Chenoweth, L., King, M. T., Jeon, Y.-H., Brodaty, H., Stein-Parbury, J., Norman, R., . . . Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology, 8*(4), 317-325.

CIOMS. (2002). International ethical guidelines for biomedical research involving human subjects. *Bulletin of medical ethics*(182), 17-23.

Clarke, A. (2000). Using biography to enhance the nursing care of older people. *British Journal of Nursing, 9*(7), 429-433.

Clarke, A., J. Hanson, E., & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing, 12*(5), 697-706.

Colomer, J., & de Vries, J. (2016). Person-centred dementia care: a reality check in two nursing homes in Ireland. *Dementia (London), 15*(5), 1158-1170. doi:10.1177/1471301214556132

Davis, D. H. J. (2004). Dementia: sociological and philosophical constructions. *Social Science & Medicine, 58*(2), 369-378. doi:10.1016/s0277-9536(03)00202-8

Delmar, C. (2012). The excesses of care: a matter of understanding the asymmetry of power. *Nursing Philosophy, 13*(4), 236-243.

Dewing, J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing, 3*(1), 3-13.

Doyle, P. J., & Rubinstein, R. L. (2013). Person-centered dementia care and the cultural matrix of othering. *The Gerontologist, 54*(6), 952-963.

Edvardsson, D., Sandman, P., & Borell, L. (2014). Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain, and stress of conscience. *International Psychogeriatrics, 26*(7), 1171-1179.

Edvardsson, D., Varrailhon, P., & Edvardsson, K. (2014). Promoting person-centeredness in long-term care: An exploratory study. *Journal of gerontological nursing*. https://doi.org/10.3928/00989134-20131028-03

Edvardsson, D., Winblad, B., & Sandman, P.-O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology, 7*(4), 362-367.

Ellis-Stoll, C. C., & Popkess-Vawter, S. (1998). A concept analysis on the process of empowerment. *Advances in Nursing Science, 21*(2), 62-68.

Epp, T. D. (2003). Person-centred dementia care: A vision to be refined. *The Canadian Alzheimer Disease Review, 5*(3), 14-19.

Fortinsky, R. H., & Downs, M. (2014). Optimizing person-centered transitions in the dementia journey: A comparison of national dementia strategies. *Health Affairs, 33*(4), 566-573.

Fossey, J., Masson, S., Stafford, J., Lawrence, V., Corbett, A., & Ballard, C. (2014). The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia. *International journal of geriatric psychiatry, 29*(8), 797-807.

Galik, E. M., Resnick, B., & Pretzer-Aboff, I. (2009). 'Knowing what makes them tick': motivating cognitively impaired older adults to participate in restorative care. *International journal of nursing practice, 15*(1), 48-55.

Garratt, S., & Hamilton-Smith, E. (1995). *Rethinking dementia: An Australian approach*. Melbourne: Ausmed Publications.

Gedde-Dahl, T. W. (2001). Empowerment - styrking av mestring? *Tidskriftet Den Norske Legeforeningen, 121*, 628.

Glesne, C. (2006). *Becoming qualitative researchers : an introduction* (3rd ed. ed.). Boston: Pearson/Allyn & Bacon.

Goldsmith, M. (1996). *Hearing the voice of people with dementia: Opportunities and obstacles*. London and Bristol: Jessica Kingsley.

Grbich, C. (1999). *Qualitative research in health : an introduction*. London: Sage.

Griffiths, A. W., Surr, C. A., Creese, B., Garrod, L., & Chenoweth, L. (2018). The development and use of the assessment of dementia awareness and person-centred care training tool in long-term care. *Dementia*, 1471301218768165.

Hammersley, M., & Atkinson, P. (2007). *Ethnography : principles in practice* (3rd ed. ed.). London: Routledge.

Harding, E., Wait, S., & Scrutton, J. (2015). The state of play in person-centred care. *London: The Health Policy Partnership*.

Heggestad, A. K. T., Nortvedt, P., & Slettebø, Å. (2013). 'Like a prison without bars' Dementia and experiences of dignity. *Nursing ethics, 20*(8), 881-892.

Heggestad, A. K. T., Nortvedt, P., & Slettebø, Å. (2015). Dignity and care for people with dementia living in nursing homes. *Dementia, 14*(6), 825-841.

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

Helleberg, K. M., & Hauge, S. (2014). "Like a dance": performing good care for persons with dementia living in institutions. *Nurs Res Pract, 2014*, 905972. doi:10.1155/2014/905972

Higgins, P. (2013). Involving people with dementia in research. *Nursing times, 109*(28), 20.

Hill, H. (2004). Talking the talk but not walking the walk: barriers to person centred care in dementia. PHD. Retrieved from: http://arrow.latrobe.edu.au:8080/vital/access/manager/Repository/latrobe:19675

Hill, H. (2008). *Talking the talk but not walking the walk: barriers to person centred care in dementia*: VDM Verlag 1st edition.

Holland, S., & Kydd, A. (2015). Ethical issues when involving people newly diagnosed with dementia in research.(Report). *22*(4), 25. doi:10.7748/nr.22.4.25.e1308

Hunter, P. V., Hadjistavropoulos, T., & Kaasalainen, S. (2016). A qualitative study of nursing assistants' awareness of person-centred approaches to dementia care. *Ageing & Society, 36*(6), 1211-1237.

Innes, A. (2002). The social and political context of formal dementia care provision. *Ageing & Society, 22*(4), 483-499.

Innes, A. (2009). *Dementia Studies: A Social Science Perspective* (S. Books Ed.). London: SAGE Publications Ltd.

Innes, A., Macpherson, S., & McCabe, L. (2006). *Promoting person-centred care at the front line*: York: Joseph Rowntree Foundation.

Jutkowitz, E., Brasure, M., Fuchs, E., Shippee, T., Kane, R. A., Fink, H. A., . . . Kane, R. L. (2016). Care-Delivery Interventions to Manage Agitation and Aggression in Dementia Nursing Home and Assisted Living Residents: A Systematic Review and Meta-analysis. *Journal of the American Geriatrics Society, 64*(3), 477-488.

Kaufman, S. R., & Morgan, L. M. (2005). The anthropology of the beginnings and ends of life. *Annu. Rev. Anthropol., 34*, 317-341.

Kielmann, K., Cataldo, F., & Seeley, J. (2012). Introduction to qualitative research methodology: A training manual. *United Kingdom: Department for International Development (DfID)*.

Kirkevold, M., Holter, I., & Burås-Leine, C. (2013). Gjenreis helsefagenes verdigrunnlag. *Sykepleien, 5*, 64-65.

Kitwood, T. (1997). *Dementia reconsidered : the person comes first*. Buckingham: Open University Press.

Kleiven, O. T., Kyte, L., & Kvigne, K. (2016). Sykepleieverdier under press? *Nordisk sygeplejeforskning, 6*(04), 311-326.

Kontos, P. C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing & Society, 24*(6), 829-849.

Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia, 4*(4), 553-570.

Kontos, P. C., & Naglie, G. (2007). Bridging theory and practice: Imagination, the body, and person-centred dementia care. *Dementia, 6*(4), 549-569.

Kristiansen, M., Westeren, K. I., Obstfelder, A., & Lotherington, A. T. (2016). Coping with increased managerial tasks: tensions and dilemmas in nursing leadership. *Journal of Research in Nursing, 21*(7), 492-502.

Kristoffersen, M., & Friberg, F. (2016). Transformasjonsledelse og økte effektivitetskrav i sykepleien. *Nordic Journal of Nursing Research, 36*(1), 13-19.

Leibing, A. (2006). Divided Gazes. *Thinking about dementia: Culture, loss, and the anthropology of senility*, 240.

Liamputtong. (2011). *Focus Group Methodology: Principles and Practice*. London: United Kingdom: SAGE Publications Ltd.

Livingston, G., Kelly, L., Lewis-Holmes, E., Baio, G., Morris, S., Patel, N., . . . Cooper, C. (2014). A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia. *Health Technology Assessment (Winchester, England), 18*(39), 1-226.

Malmedal, W., Hammervold, R., & Saveman, B.-I. (2014). The dark side of Norwegian nursing homes: Factors influencing inadequate care. *The Journal of Adult Protection, 16*(3), 133-151.

Malmedal, W., Ingebrigtsen, O., & Saveman, B. I. (2009). Inadequate care in Norwegian nursing homes–as reported by nursing staff. *Scandinavian Journal of Caring Sciences, 23*(2), 231-242.

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *Lancet, 358*(9280), 483-488. doi:10.1016/s0140-6736(01)05627-6

Martin, G. W., & Younger, D. (2000). Anti oppressive practice: a route to the empowerment of people with dementia through communication and choice. *Journal of Psychiatric and Mental Health Nursing, 7*(1), 59-67.

Maxwell, J. A. (2012). *Qualitative research design: An interactive approach* (Vol. 41). Thousand Oaks, California: Sage publications.

McCabe, M., Davison, T., & George, K. (2007). Effectiveness of staff training programs for behavioral problems among older people with dementia. *Aging and Mental Health, 11*(5), 505-519.

McCormack, B. (2003). A conceptual framework for person-centred practice with older people. *International journal of nursing practice, 9*(3), 202-209.

McCormack, B. (2004). Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing, 13*(s1), 31-38. doi:10.1111/j.1365-2702.2004.00924.x

McCormack, B., Borg, M., Cardiff, S., Dewing, J., Jacobs, G., Janes, N., . . . Wilson, V. (2015). Person-centredness - the 'state' of the art. *International Practice Development Journal, 5*.

McCormack, B., Karlsson, B., Dewing, J., & Lerdal, A. (2010). Exploring person-centredness: a qualitative meta-synthesis of four studies. *Scandinavian Journal of Caring Sciences, 24*(3), 620-634.

McCormack, B., & McCance, T. (2010). *Person-Centred Nursing, Theory and Practice*. Oxford: Wiley-Blackwell.

Merriam-Webster. (2018). Retrieved from https://www.merriam-webster.com/dictionary/see

Mjørud, M., Kirkevold, M., Røsvik, J., Selbæk, G., & Engedal, K. (2014). Variables associated to quality of life among nursing home patients with dementia. *Aging & mental health, 18*(8), 1013-1021.

Moen, K., & Middelthon, A.-L. (2015). Chapter 10 - Qualitative Research Methods A2 - Laake, Petter. In H. B. Benestad & B. R. Olsen (Eds.), *Research in Medical and Biological Sciences* (pp. 321-378). Amsterdam: Academic Press.

Moore, L., Britten, N., Lydahl, D., Naldemirci, Ö., Elam, M., & Wolf, A. (2017). Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian Journal of Caring Sciences, 31*(4), 662-673. doi:10.1111/scs.12376

Morgan, S., & Yoder, L. H. (2012). A concept analysis of person-centered care. *Journal of Holistic Nursing, 30*(1), 6-15.

Moser, I. (2008). Making Alzheimer's disease matter. Enacting, interfering and doing politics of nature. *Geoforum, 39*(1), 98-110.

Moser, I. (2011). Dementia and the limits to life: anthropological sensibilities, STS interferences, and possibilities for action in care. *Science, Technology, & Human Values, 36*(5), 704-722.

Naldemirci, Ö., Wolf, A., Elam, M., Lydahl, D., Moore, L., & Britten, N. (2017). Deliberate and emergent strategies for implementing person-centred care: a qualitative interview study with researchers, professionals and patients. *BMC health services research, 17*(1). doi:DOI 10.1186/s12913-017-2470-2

National Commission for the Proptection of Human Subjects of Biomedicaland Behavioral Research, B., Md. (1978). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*: Superintendent of Documents.

Neby, S. (2016). Marketization and accountability: Lessons from the reforming Norwegian healthcare system *Public Accountability and Health Care Governance* (pp. 65-89). London: Palgrave Macmillan.

Newman, J. (2000). Beyond the New Public Management? Modernizing Public Services. *New Managerialism, New Welfare?*, 45-61. London, Thousand Oaks: Sage Publications

Newman, S., & Lawler, J. (2009). Managing health care under New Public Management: A Sisyphean challenge for nursing. *Journal of Sociology, 45*(4), 419-432.

Norwegian Directorate of Health and Social Affairs. (2007). Glemsk, men ikke glemt. *Om dagens situasjon og fremtidens utfordringer for å styrke tjenestetilbudet til personer med demens. IS-1486. Sosial-og Helsedirektoratet, Oslo.*

Norwegian Ministry of Health and Care Services. (2008). *Dementia plan 2015 - Making the most of good days*. Oslo: Ministry of Health and Care Services.

Norwegian Ministry of Health and Care Services. (2015). Dementia plan 2020. A more dementia-friendly society. Oslo: Ministry of Health and Care Services.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods, 16*(1), 1609406917733847.

Penrod, J., Yu, F., Kolanowski, A., Fick, D. M., Loeb, S. J., & Hupcey, J. E. (2007). Reframing person-centered nursing care for persons with dementia. *Research and theory for nursing practice, 21*(1), 57.

Pierce, R. (2010). A changing landscape for advance directives in dementia research. *Social Science & Medicine, 70*(4), 623-630. doi:10.1016/j.socscimed.2009.10.037

Pitkin, J. (2016). Using validation to understand the experience of dementia. *Nursing And Residential Care, 18*(9), 487-490.

Pol-Grevelink, A., Jukema, J., & Smits, C. (2012). Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *International journal of geriatric psychiatry, 27*(3), 219-229.

Rokstad, A. M. M., Døble, B. S., Engedal, K., Kirkevold, Ø., Benth, J. Š., & Selbæk, G. (2017). The impact of the Dementia ABC educational programme on competence in person-centred dementia care and job satisfaction of care staff. *International Journal of Older People Nursing, 12*(2).

Rokstad, A. M. M., Røsvik, J., Kirkevold, Ø., Selbaek, G., Benth, J. S., & Engedal, K. (2013). The effect of person-centred dementia care to prevent agitation and other neuropsychiatric symptoms and enhance quality of life in nursing home patients: a 10-month randomized controlled trial. *Dementia and geriatric cognitive disorders, 36*(5-6), 340-353.

Rokstad, A. M. M., & Vatne, S. (2011). Dementia care mapping--en mulighet for refleksjon og utvikling. *Norwegian Journal of Clinical Nursing/Sykepleien Forskning*(1).

Rokstad, A. M. M., Vatne, S., Engedal, K., & Selbæk, G. (2015). The role of leadership in the implementation of person-centred care using Dementia Care Mapping: a study in three nursing homes. *Journal of nursing management, 23*(1), 15-26.

Rosvik, J., Engedal, K., & Kirkevold, Ø. (2014). Factors to make the VIPS practice model more effective in the treatment of neuropsychiatric symptoms in nursing home residents with dementia. *Dementia and geriatric cognitive disorders, 37*(5-6), 335-346.

Røsvik, J., Kirkevold, M., Engedal, K., Brooker, D., & Kirkevold, Ø. (2011). A model for using the VIPS framework for person-centred care for persons with dementia in nursing homes: a qualitative evaluative study. *International Journal of Older People Nursing, 6*(3), 227-236.

Sabat, S. R. (1994). Excess disability and malignant social psychology: A case study of Alzheimer's disease. *Journal of community & applied social psychology, 4*(3), 157-166.

Samdal, O., Wold, B., Harris, A., & Torsheim, T. (2017). *Stress og mestring*. Retrieved from https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/1392/Stress og mestring IS-2655.pdf. Oslo: Norwegian Directorate of Health and Social Affairs

Sandman, P.-O., Edvardsson, D., & Winblad, B. (2006). Care of patients in the severe stage of dementia. *Clinical Diagnosis and Management of Alzheimer's Disease*, 233-246.

Selbæk, G., Kirkevold, Ø., & Engedal, K. (2008). The course of psychiatric and behavioral symptoms and the use of psychotropic medication in patients with dementia in Norwegian nursing homes—a 12-month follow-up study. *The American Journal of Geriatric Psychiatry, 16*(7), 528-536.

Silverman, D. (2013). *Doing qualitative research* (4th ed. ed.). Los Angeles, Calif: Sage.

Slater, L. (2006). Person-centredness: a concept analysis. *Contemporary Nurse, 23*(1), 135-144.

Smebye, K. L., & Kirkevold, M. (2013). The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study. *BMC nursing, 12*(1), 29.

Smebye, K. L., Kirkevold, M., & Engedal, K. (2012). How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC health services research, 12*(1), 241.

Smythe, A., Bentham, P., Jenkins, C., & Oyebode, J. R. (2015). The experiences of staff in a specialist mental health service in relation to development of skills for the provision of person centred care for people with dementia. *Dementia, 14*(2), 184-198.

Stranz, A., & Sörensdotter, R. (2016). Interpretations of person-centered dementia care: Same rhetoric, different practices? A comparative study of nursing homes in England and Sweden. *Journal of aging studies, 38*, 70-80.

Talbot, R., & Brewer, G. (2016). Care assistant experiences of dementia care in long-term nursing and residential care environments. *Dementia (London), 15*(6), 1737-1754. doi:10.1177/1471301215576416

Taylor, J. S. (2008). On recognition, caring, and dementia. *Medical anthropology quarterly, 22*(4), 313-335.

Tingvoll, W.-A., Sæterstrand, T., & McClusky, L. M. (2016). The challenges of primary health care nurse leaders in the wake of New Health Care Reform in Norway. *BMC nursing, 15*(1), 66. https://doi.org/10.1186/s12912-016-0187-x

van der Cingel, M., Brandsma, L., van Dam, M., van Dorst, M., Verkaart, C., & van der Velde, C. (2016). Concepts of person-centred care: a framework analysis of five studies in daily care practice. *International Practice Development Journal, 6*(2).

WHO. (1998). Health promotion glossary. Retrieved from: http://www.who.int/healthpromotion/about/HPG/en/

WHO. (2012). *Dementia: a public health priority*: World Health Organization.

WHO. (2017a). Dementia Key Facts. Retrieved from http://www.who.int/news-room/fact-sheets/detail/dementia

WHO. (2017b). Global action plan on the public health response to dementia 2017–2025.

Zimmerman, M. A. (2000). Empowerment theory *Handbook of community psychology* (pp. 43-63). Boston: Springer.

APPENDIX 1: Interview Guide

Semi-structured open-ended questions. The intent is that the interview will be more of a dialogue, hence the sequence of questions and which questions will be raised, will vary depending on the flow of the conversation.

1.1 IN-DEPTH INTERVIEW GUIDE FOR HEALTH PERSONNEL

Background.

- Can you please tell me a bit about yourself? (Age, occupation within the nursing home, type and level of education, length of work in the current nursing home, other nursing homes) *Probe for more details if necessary*

Work environment.

- How long have you been working with dementia care? *Probe for how and/or why path of work was chosen*
- How do you view dementia as a condition?
- Could you describe a typical day at work? *Probe for any relevant information for e.g. daily tasks, distribution of work tasks, teamwork, activities with residents, routines etc.*
- Does your institution have a specific vision when it comes to dementia care?

Person-centred care.

- Can you please tell me a bit more about your education? (specific training programmes, length of training programme, aim of training) *Probe for more details on training programme (if any)*
    - *If training is relevant to person-centred care, probe for*:
        - Skills attained, knowledge gained, strengths/weaknesses of the program, expectations
- Is the concept of person-centred care for persons with dementia familiar to you?
    - if yes;
        - How was this knowledge acquired? *Probe for more details on knowledge if necessary*
        - How do you understand/perceive PCC? *Probe for details*
        - Do you use it? (Why, why not, specific examples?) *Probe for how this knowledge is applied in practice using real examples of resident-staff interactions*
        - Is this approach to care practiced by others you know? *Probe for yes, no, why, why not*
        - What do you perceive as good care?
    - if no;
        - How is care mainly practiced? (day to day activities) *probe for examples of interactions with residents situations*
        - What do you perceive as good care? *Probe for examples when relevant*

(Note: If PCC is practised, probe for perceived strengths and weaknesses, perceived positive effects on staff/resident, how long it's been implemented, how it is viewed etc.)

Dementia.

- How would you describe/view dementia?
- How do you view and interpret these behaviors?
- How do you usually deal with a difficult situation?
    - Any specific strategies?
    - Use of medication? *Probe for when and how often*

Barriers. (Specifically relevant if knowledge of PCC is present but not applied in practice)

- Do you experience any work related problems? (more specifically concerning use of PCC) *Probe for necessary details*
    - if yes;
        - How do you feel discussing these issues with others from work? *If these topics are discussed probe for whom they are discussed with and what type of solutions have been raised*
- There are many reasons for why PCC is found difficult to implement. According to your experience in this institution, what are some of the reasons? What would you think would be needed to successfully implement PCC?
    - if resources is given as a reason;
        - Assuming all resources were met, would you need anything else to implement person-centred care?

End. Are there any other points we have missed out that you would like to raise? Do you have any questions?

1.2 IN-DEPTH INTERVIEW GUIDE FOR MANAGERS

Background.

- Can you please tell me a bit about yourself? (Age, occupation within the nursing home, type and level of education, length of work in the current nursing home, other nursing homes) *Probe for more details if necessary*

Work environment.

- (If specifically, manager for dementia facility) How long have you been working with dementia care? *Probe for how and/or why path of work was chosen*
- How do you view dementia as a condition?
- Could you describe a typical day at work? Closeness to staff? *Probe for any relevant information*
- Does your institution have a specific vision when it comes to dementia care? What do you perceive as good care?

Person-centred care.

- Can you please tell me a bit more about your education? (specific training programmes, length of training programme, aim of training) *Probe for more details on training programme (if any)*
    - *If training is relevant to person-centred care, probe for*:
        - Skills attained, knowledge gained, strengths/weaknesses of the program, expectations

- Is the concept of person-centred care for persons with dementia familiar to you?
    - if yes;
        - How was this knowledge acquired? *Probe for more details on knowledge if necessary*
        - How do you understand/perceive PCC? *Probe for details*
        - Is PCC used at this institution? (why, why not) *Probe for how this knowledge is applied in practice*
        - Is this approach to care practiced by all staff? *Probe for yes, no, why, why not*
    - if no;
        - What (if any) vision for care is applied in your institution?
        - How is care mainly practiced?

(Note: If PCC is practised at the institution, probe for perceived strengths and weaknesses, perceived positive effects on staff/resident, how long it's been implemented, how it is viewed etc.)

Dementia.

- How would you describe/view dementia?
- How do you view and interpret behaviours?
- How would you like staff to deal with a difficult situation?
    - Any specific strategies?

Barriers. (Specifically relevant if knowledge of PCC is present but not applied in practice)

- Do you/your staff experience any work related problems? (more specifically concerning use of PCC) *Probe for necessary details*
    - if yes;
        - How do you/they feel discussing these issues with others from work? *If these topics are discussed probe for whom they are discussed with and what type of solutions have been raised*
- There are many reasons for why PCC is found difficult to implement. According to your experience in this institution, what are some of the reasons? What would you need to successfully implement PCC?
    - if resources is given as a reason;
        - Assuming all resources were met, would your institution need anything else to implement person-centred care?

End. Are there any other points we have missed out that you would like to raise? Do you have any questions?

APPENDIX 2: Consent forms

PERSONSENTRERT DEMENSOMSORG: FRA OMSORGSTEORI TIL OMSORGSPRAKSIS

FORESPØRSEL OM DELTAGELSE I FORSKNINGSPROSJEKTET

Du er invitert til å delta i et forskningsprosjekt som omhandler bruk av personsentrert omsorg i norske sykehjem. Som ansatt ved demensavdeling har du et unikt perspektiv som kan informere dette prosjektet. Jeg vil gjerne lære hvordan du som helsepersonell oppfatter demensomsorg og personsentrert omsorg. Jeg vil også gjerne vite i hvilken grad personsentrert omsorg forstås og anvendes i praksis. Din deltakelse kan bidra til å kartlegge bruk av personsentrert omsorg, og informere fremtidige tiltak.

Resultatene av prosjektet inngår som del av et Masterstudium i Internasjonal Helse ved Institutt for Helse og Samfunn og vil bli presentert i en masteroppgave.

Student: Hedda Olesen Arfaoui
Institusjon: Institutt for Helse og Samfunn, Universitetet i Oslo
Project: Personsentrert demensomsorg: Fra omsorgsteori til omsorgspraksis

DEL 1: BAKGRUNN OG FORMÅL

HVA INNEBÆRER PROSJEKTET?

Masterprosjektet er en kvalitativ studie med fokus på omsorg knyttet til personer med demens i norske sykehjem. Studien vil foregå på 2 forskjellige sykehjem i Oslo-regionen. Målet for studien er å forstå bruken av personsentrert omsorg i demensomsorg og hvordan kunnskap om denne teorien inngår i praksis og i opplæring av helsepersonell. Gjennom observasjoner og semistrukturerte dybdeintervjuer med ledelse og ansatte , har studien som mål å få innsikt i deres erfaringer og forståelse av egen praksis og hvordan personsentrert teori og opplæring forstås, brukes eller motvirkes i deres profesjonelle hverdag.

Feltarbeid ved din institusjon skal etter planen avsluttes i oktober 2017.

HVA INNEBÆRER DELTAKELSE I STUDIEN?

Datainnsamling skjer i form av strukturerte dybdeintervjuer og observasjoner av daglige rutiner på sykehjemmene. Vi kan sammen avtale sted og dato for intervjuet. Spørsmålene som stilles i intervjuene omhandler hvordan du som ansatt opplever demensomsorg og eventuell bruk av personsentrert omsorg. Samtalen vil dreie seg om omsorgspraksis og strategier som brukes i samspillet mellom ansatte og beboere. Jeg vil gi deg tid til å dele din kunnskap, dine tanker, erfaringer og bekymringer angående bruk av personsentrert omsorg i din profesjonelle hverdag som ansatt ved en demensavdeling.

Dersom du er komfortabel med det, vil intervjuet bli tatt opp med båndopptaker. Du vil ikke bli identifisert med navn og ingen andre enn meg selv vil ha tilgang til innsamlet materiale.

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Alle opplysningene vil bli behandlet uten navn, fødselsnummer, navn på institusjonene eller andre direkte gjenkjennende opplysninger som kan knyttes til enkeltpersoner og/eller institusjon. Data som er innsamlet vil bli anonymisert ved koding, mao kun alder, stillling og kjønn vil fremkomme.

Intervjuene som er tatt opp på bånd, vil bli transkribert så raskt som mulig og lastet opp på en passordbeskyttet server ved Universitetet i Oslo. Intervjuene vil deretter bli slettet fra båndopptaker. Håndskrevne feltnotater vil oppbevares i et låst skap på Insitutt for Helse og Samfunn og all nedskreven informasjon vil underveis være anonymisert. Ved masterprosjektets slutt (etter endelig eksamen i juni 2018) vil alle skriftlige og elektroniske dokumenter som kan knyttes til prosjektet bli destruert.

FRIVILLIG DELTAKELSE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Jeg vil gi deg en mulighet ved slutten av intervjuet til å gjennomgå kommentarene dine, og du kan be om å endre eller fjerne deler av dem hvis du ikke er enig med notatene, eller hvis jeg ikke forstod deg riktig. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du trekker deg, vil alle opplysninger om deg bli fjernet.

KONTAKTPERSON

Dersom du ønsker å delta eller har spørsmål til studien, kan du kontakte prosjektansvarlig, Hedda Olesen Arfaoui på følgende epost adresse: h.o.arfaoui@studmed.uio.no eller via telefon: +47 45 42 72 79. Du kan også ta kontakt med prosjektveileder, Benedikte V. Lindskog, på epost adressse b.v.lindskog@medisin.uio.no eller biveileder, Anne Marie Mork Rokstad, anne.marie.rokstad@aldringoghelse.no

GODKJENNING

Studien er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.

DEL 2: SAMTYKKE TIL DELTAKELSE I STUDIEN

Prosjektdeltaker:

Jeg har mottatt informasjon om studien, og er villig til å delta.

Deltakers navn ______________________

Deltakers signatur____________________

Sted & dato_________________________

Prosjektansvarlig:

Jeg bekrefter å ha gitt informasjon om prosjektet. Jeg bekrefter at deltakeren ble gitt anledning til å stille spørsmål om studien. Jeg bekrefter at personen ikke har blitt tvunget til å gi samtykke, og samtykket er gitt fritt og frivillig.

Prosjektleders navn ________________________

Prosjektleders signatur______________________

Sted & dato _______________________________

APPENDIX 3: Assessment letters

3.1 NSD: Norwegian Centre for Research Data

Benedicte Victoria Lindskog
Institutt for helse og samfunn Universitetet i Oslo
Postboks 1130 Blindern
0318 OSLO

Vår dato: 09.06.2017 Vår ref: 54434 / 3 / STM Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 15.05.2017. Meldingen gjelder prosjektet:

54434	*Person-Centered Dementia-Care: From Care Theory to Care Practice*
Behandlingsansvarlig	*Universitetet i Oslo, ved institusjonens øverste leder*
Daglig ansvarlig	*Benedicte Victoria Lindskog*
Student	*Hedda Olesen Arfaoui*

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvernombud/meld_prosjekt/meld_endringer.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 30.06.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Siri Tenden Myklebust

Kontaktperson: Siri Tenden Myklebust tlf: 55 58 22 68
Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

3.2 REK: The regional Committees for Medical and Health Research Ethics

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 54434

REK har vurdert at prosjektet ikke er fremleggelsespliktig (REK/sør-øst/2017/868).

UTVALG OG REKRUTTERING

Utvalget består av helsepersonell og ledere ved to utvalgte sykehjem. Studenten vil kontakte ledere ved sykehjemmet, som vil informere de ansatte om studien. Personvernombudet minner om at forespørsel må rettes på en slik måte at frivilligheten ved deltakelse ivaretas.

DATAINNSAMLING

Datamaterialet sames inn gjennom intervjuer med helsepersonell og ledelse.

Personvernombudet legger til grunn at taushetsplikten ikke er til hinder for behandling av personopplysninger i prosjektet. Vi anbefaler at helsepersonell som intervjues minnes om at de har taushetsplikt og således ikke kan oppgi informasjon om enkeltbeboere/pårørende under intervjuene.

Studenten vil også gjennomføre observasjoner av daglig praksis blant helsepersonell på de to utvalgte sykehjemmene. Dersom enkelte av de ansatte ikke ønsker å bli observert, vil studenten legge opp feltarbeidet slik at observasjonene kun gjennomføres de dagene der de som har samtykket jobber. Vi legger dette til grunn.

ANDRE TILLATELSER

Masterstudenten vil ikke ha direkte kontakt eller interaksjon med pasienter under feltarbeid på sykehjemmene. Fokuset vil ikke være på beboerne, men være rettet mot helsepersonell og hvordan de utfører sine arbeidsoppgaver. Selv om masterstudenten ikke skal registrere personopplysninger om pasientene, må ledelsen ved sykehjemmene ta stilling til om de kan gi student adgang til å observere, (ved at student signerer en taushetserklæring), eller om det må søkes om dispensasjon fra taushetsplikten fra aktuell myndighet (REK). Vi legger til grunn at student og veileder avklarer nødvendigheten av en dispensasjon med REK. En eventuell dispensasjon skal ettersendes til personvernombudet@nsd.no.

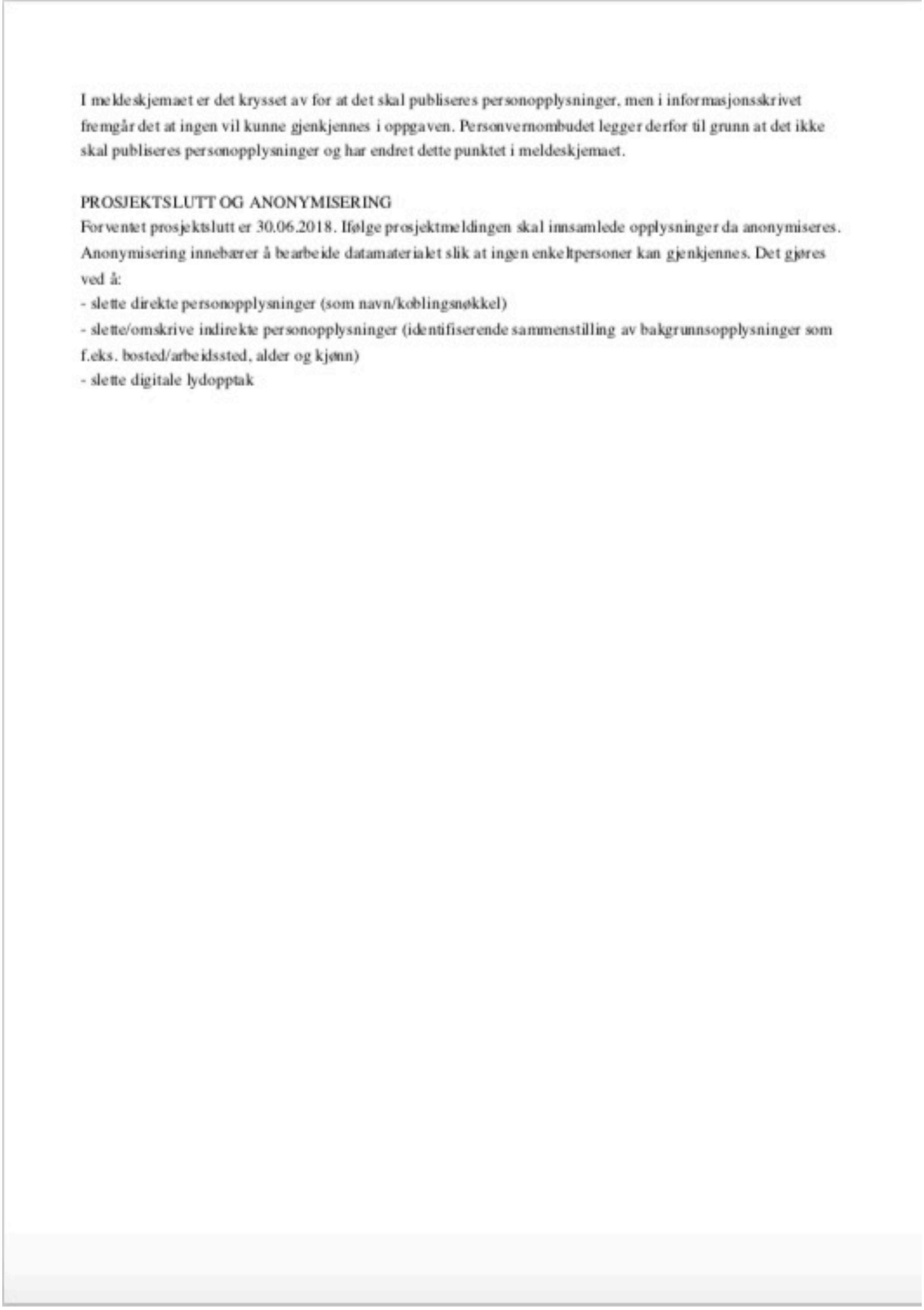
INFORMASJON OG SAMTYKKE

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er greit utformet, men det må også opplyses om at data anonymiseres ved prosjektslutt, jf. opplysningene oppgitt i meldeskjemaet.

DATASIKKERHET

Personvernombudet legger til grunn at student etterfølger Universitetet i Oslo sine interne rutiner for datasikkerhet.

PUBLISERING



I meldeskjemaet er det krysset av for at det skal publiseres personopplysninger, men i informasjonsskrivet fremgår det at ingen vil kunne gjenkjennes i oppgaven. Personvernombudet legger derfor til grunn at det ikke skal publiseres personopplysninger og har endret dette punktet i meldeskjemaet.

PROSJEKTSLUTT OG ANONYMISERING
Forventet prosjektslutt er 30.06.2018. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette digitale lydopptak