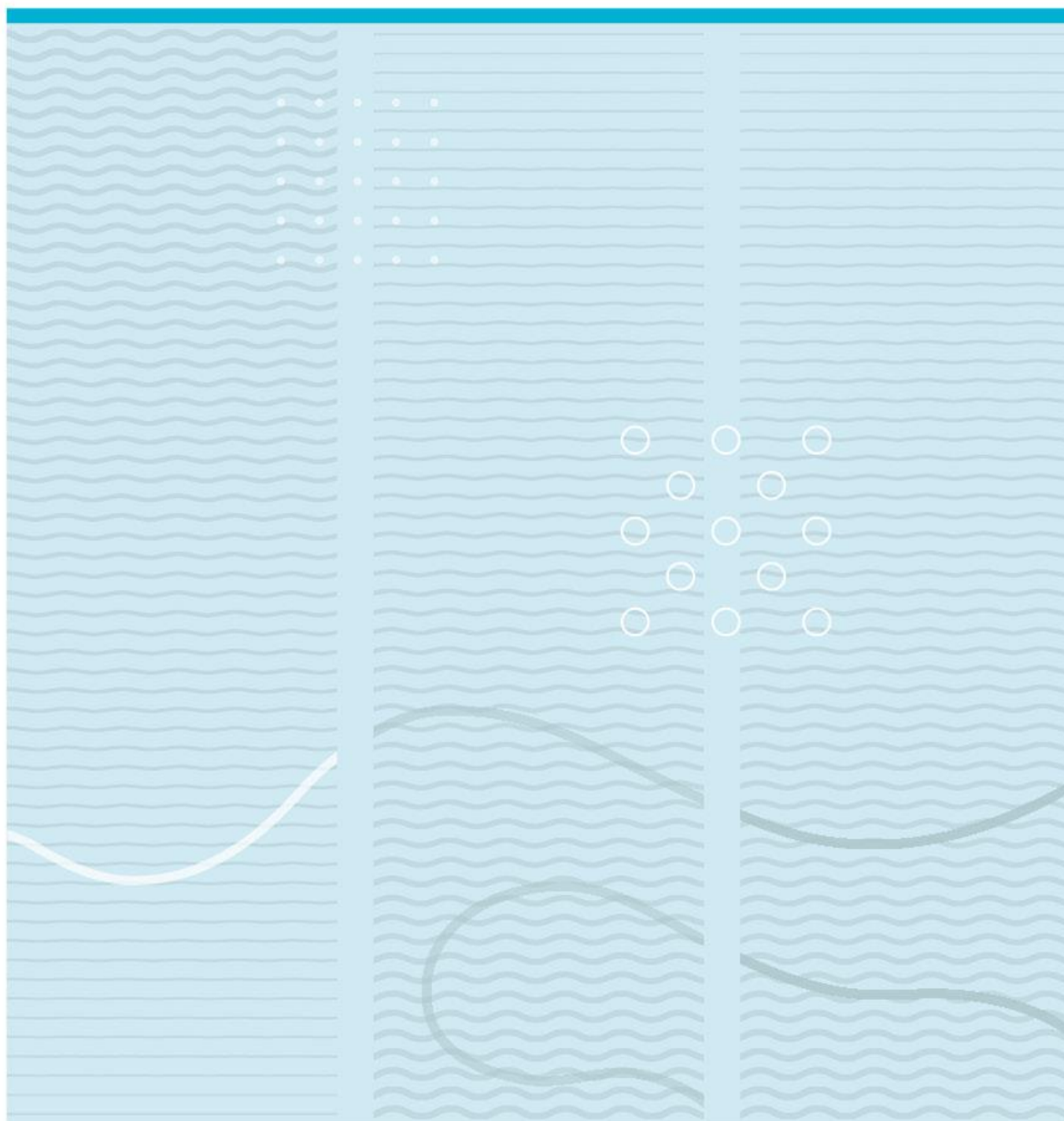


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Managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia during the coronavirus pandemic: A qualitative study



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This thesis is worth 30 study points.

Abstract

Elderly with dementia is one of the most vulnerable user groups. Comprehensive and overlapping symptoms can affect the entire life situation. This study investigates the experiences of home care workers in managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia during the corona pandemic. It aims to highlight some of the ethical and practical issues that were encountered, the concrete measures that were implemented, and future action plans that might be helpful in attaining a more dignified and person-centered home nursing care in the future.

This qualitative research study has an explorative and descriptive design. Nine (9) home care workers from seven (7) home care bases within two municipalities in South-eastern Norway participated in focus group interviews (FGIs). Data were analyzed using thematic analysis. Findings show that homecare workers had varying views and understanding of the term “psychosocial needs» and whose responsibility its management was. Furthermore, home care workers met ethical dilemmas concerning confidentiality, deviations from rules and guidelines to meet users’ need for social companionship, difficulty in implementing infection control measures and providing treatment, and the feeling of being torn between the sense of duty and obligation and their own personal safety. Respondents also reported that providing person-centered psychosocial healthcare required interpersonal and organizational skills and competence. This study concludes that the coronavirus pandemic had brought about immense challenges for the management of the psychosocial needs of home-dwelling elderly with dementia in Norway. There is a need to clarify what psychosocial needs are, to address the ethical issues experienced during the COVID-19 pandemic, and to utilize previous experiences as a learning tool in order to provide a more person-centered psychosocial healthcare in the future.

Keywords: COVID-19 pandemic, person-centered care, psychosocial needs, home-dwelling elderly with dementia, home nursing care

Sammendrag

Eldre med demens er en av de mest sårbare tjenestebrukerne grunnet komplisert sykdomsforløp. Overlappende symptomer kan påvirke hele livssituasjonen. Denne studien undersøker hvilke erfaringer hjemmetjenesteutøvere hadde ved ivaretagelse av psykososiale behov hos COVID-19 isolerte hjemmeboende eldre med demens under korona pandemien. Den vil belyse etiske og praktiske dilemmaer, de konkrete tiltakene som ble utført og hvordan disse erfaringene kan brukes for å kunne tilby en mer verdifull og person-sentrert hjemmesykepleie til eldre personer med demens.

I denne studien anvender jeg kvalitativ metode med eksplorativ og deskriptiv tilnærming. Ni (9) hjemmetjenesteutøvere fra syv (7) baser innen to kommuner i Sør-Øst Norge deltok i fokusgruppeintervjuer (FGI). Datamaterialet ble analysert ved bruk av *thematic analysis*. Resultatene viser at hjemmetjenesteutøvere hadde ulike perspektiver og forståelse av begrepet «psykososiale behov» og hvem som hadde ansvar for ivaretagelsen av disse behovene. Videre hadde de møtt etiske dilemmaer knyttet til taushetsplikten, bruk av skjønn for å ivareta behovene for sosialt samvær mot det å følge regler og forskrifter om smittevern, utfordringer knyttet til implementering av smitteverntiltak og behandlingsprosedyrer, og følelsen av å måtte velge mellom det å gjennomføre plikten til å jobbe og det å ivareta egen sikkerhet og egen helse. Informantene rapporterte også at personsentrert ivaretagelse av psykososiale behov krevde interpersonal og organisatorisk ferdigheter og kompetanse. Studien konkluderer at koronapandemien medførte store utfordringer knyttet til ivaretagelse av psykososiale behov hos hjemmeboende eldre med demens i Norge. Det er behov for å avklare hva «psykososiale behov» egentlig betyr, diskutere de etiske dilemmaene som var erfart under korona pandemien og vurdere hvordan disse erfaringene kan brukes som læringsmateriale for å kunne yte personsentrerte helsetjenester som skal ivareta de psykososiale behovene.

Nøkkelord: koronapandemi, person-sentrert sykepleie, psykososiale behov, hjemmeboende eldre med demens, hjemmetjenester

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Foreword

Fourteen years ago, as a young student-assistant in the College Library of the University of the Philippines, I came across a booklet full of inspiring quotations. From there, I found a saying that I've carried with me for a very long time: "You cannot give what you do not have". It served as a guiding philosophy, motivating me to continue learning and aiming for personal growth.

I realized that I need to keep updating my knowledge and skills while finding the balance in everything, in order to give what my patients or students need. Working with the elderly is one of my many passions. This master's thesis is a pursuit of wisdom, seeking to fill the cup of healthcare workers in order to be able to meet the psychosocial needs of their patients or service users.

I would like to thank:

God Almighty, for the gift of life;

my husband, *Carl*, for supporting my ambitions, from finishing a second degree to pursuing a master's degree – you've been my rock and my inspiration;

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I'd also like to extend my sincerest gratitude to the leaders of the participating municipalities, for helping me with the recruitment process, and the participants – who keep doing a great and important job! I salute you all.

Drammen, 07.may 2023

Maerose S. Clausen Nielsen

1 Introduction

1.1 Background

In December 2019, the World Health Organization received information about the new virus which can cause severe respiratory illnesses (WHO, 2021). The new coronavirus (SARS-CoV-2) was first reported to infect inhabitants of Wuhan, China. What followed was a global pandemic and a social crisis which has impacted many, if not all, countries, politically and economically. Vulnerable groups like people living below the poverty line, older persons, persons with disabilities, youth and indigenous people were highly affected by the pandemic due to protocols and guidelines that restricted movement, job opportunities and availability of resources (United Nations DESA, n.d.).

The Norwegian government had implemented strict infection control measures to contain the spread of the COVID-19 virus, following its first recorded case on 26 February 2020 (NOU 2022:5, p.16). Approximately 1.4 million cases was recorded by the Norwegian Institute of Public Health (NIPH) since then, with around 4,000 deaths and 16,000 hospital admissions (NIPH, 2022). These numbers are relatively low compared to other European nations. However, Norway endured five waves of COVID-19 infection in a span of two years, resulting in what authorities called a «long-term crisis» with consequences for the entire population (NOU 2022:5, p.16-31). According to the official report released by the Coronavirus Commission in April 2022, the pandemic had put a major strain in hospitals and that authorities were not sufficiently prepared, in spite of the good overall management of the pandemic situation in the country and a high degree of adaptability and flexibility within the health care sector (NOU 2022:5, p.443).

After almost two years of implementation, the Norwegian government removed all regulatory measures against COVID-19 and declared coronavirus (SARS-CoV-2) as “no longer a threat to [the] health” of most of the population (Norwegian Government/*Regjeringen*, 2022). While society gradually advances to a different kind of “normal”, I couldn’t help but reflect on the experiences of home healthcare workers in managing the psychosocial needs of one of the most vulnerable usergroups – the elderly with dementia, during the COVID-19 pandemic. After the conclusive burden that the health care sector had to face, considering inadequate resources, materials and staffing (NOU 2022:5, p.1), I felt it almost imperative to contemplate on its adverse effects and its consequences in implementing person-centered psychosocial healthcare.

I became curious to know if, in the midst of prioritizing the many different needs of a user, psychosocial well-being was put into consideration, or if it was merely forgotten during the pandemic. For while it is an important aspect in holistic healthcare, restricted amount of time, implementation of infection control measures, and the urgency to treat an acute ailment, can hinder its management. Based on my personal experiences working in isolation posts, COVID-19 infection can cause an alarming impact on a dementia patient's behavior. I have observed some of them show signs of a higher level of anxiety and loneliness. A few were skeptical towards COVID-19, while others displayed an aggressive behavior and lack of willingness to comply to infection control measures and testing procedures. Furthermore, it could be challenging to ascertain if the patient's confusion and desorientation were caused by the infection itself or if it were a reaction to the treatment and preventive protocols.

For the reason that my experiences were restricted within institutional care, I became interested to delve in the subject of how psychosocial needs were met and managed by home care workers. In Norway, home is where most of elderly persons with dementia can be found. Two-thirds of the 101, 118 registered elderly with dementia in Norway live at home, and over 40 percent of them at the age of 70 years old and above who receive home care have dementia diagnosis (Gjøra, et al., 2021).

Needless to say, the number of older persons receiving home care is expected to increase in the years to come. According to Statistics Norway (*Statistisk sentralbyrå, SSB*), fewer have received institutional care from 1992-2004 (Abrahamsen & Svalund, 2005), following the action plan for elderly care of 1997 (*Handlingsplan for eldreomsorgen, St. Meld. 50, 1996-1997*). The action plan focuses on extended home-based care and housing for the elderly population, downsizing the services offered by institutions, like nursing homes, in support of the idea that older people tend to have a greater quality of life by living in their own homes. The Norwegian Directorate of Healthcare (*Helsedirektoratet, 2023, p.47*) also instructed municipal healthcare systems to equip themselves with a working plan for home treatment of COVID-19 patients, utilizing digital devices and other solutions befitting the local circumstances. Henceforth, it can be expected that home treatment and care will be functional for future COVID-19-related issues.

1.2 Review of literature

In this section, I will provide an overview of previous research related to the subject matter. Systematic search was done using databases like CINAHL, PubMed, Oria and Google Scholar. Search

words and phrases, like «Infection AND psychosocial», «Infection AND Dementia», «COVID-19 AND Dementia», were used. First and foremost, I would like to present research on how being afflicted with dementia during old age and simultaneously catching the corona virus can result to more undesirable consequences to someone's mental health. Afterwards, earlier research on management of psychosocial needs of elderly with dementia under isolation will be presented, with focus on the experiences of healthcare workers and caregivers to elderly patients with dementia. It is important to note that most of the earlier research on this topic included both home-dwelling participants and those living in long-term care facilities, like nursing homes or palliative care institutions. Only one study included in this section specified its context as «home-care».

COVID-19, old age and dementia

Elderly people with dementia belong to a high-risk group, as far as infection is concerned. On one hand, old age makes a person more vulnerable to acquiring infections, autoimmune diseases and malignant tumors (Lian, et al, 2020). This group can even develop a diminished response to vaccines due to the natural process called *immunosenescence*, where the body's immune system starts to dysfunction (Goronzy & Weyand, 2013; Wyller, 2020, p.334). It usually happens after the age of 50 (Wyller, 2020, p.334).

Meanwhile, having dementia during old age can heighten the difficulty of infection prevention and treatment. Dementia often develops or manifests as a disease in itself, or it can be confused as part of a healthy ageing process (WHO, 2023). Symptoms of dementia can be similar to, or can overlap with, symptoms of an infection, thus, making it challenging to assess a patient needing treatment.

Some studies also show that there is a correlation between pre-existing dementia diagnosis and developing severe symptoms from a COVID-19 infection. Analysis from a research study done in the United Kingdom in 2020 confirmed that dementia is the largest effect risk diagnosis in adults aged 65 years and above for risk of hospitalized COVID-19 test positivity and death within the UK Biobank Cohort of 500, 000 community volunteers aged 40-70 years (Atkins, et al, 2020).

Dementia is among the comorbidities of diseases that were found to be highly associated with COVID-19-related deaths (Williamson, et al, 2020). In a retrospective study in Italy, COVID-19 infected persons with dementia showed a 62% increased mortality rate compared with others who did not have the disease, regardless of age, with delirium and worsening functional status as the most frequent symptoms (Bianchetti, et al., 2020). This was in line with the findings of another retrospective study that was carried out in the United States of America (USA). COVID-19 patients

with dementia had a 20.99% risk for a 6-month mortality and 59.26% risk for hospitalization (Wang, et al., 2021). Aside from the increased risk of contracting the virus, the study was also able to determine that patients with black ethnicity had a higher probability of developing COVID-19 than those with white ethnicity. Furthermore, vascular dementia showed a stronger effect than other types of dementia.

Impacts on psychosocial well-being

Earlier research after the onset of the COVID-19 pandemic shows that contracting the disease had been psychologically burdensome for both the patients with dementia and their healthcare providers. However, most of these studies were done in institutions, like hospitals and nursing homes.

Taylor, et al. (2021) researched on the factors that can increase the risk of negative effects of COVID-19 lockdown on the elderly patients' psychosocial and physical health. Amongst the variables that became evident as contributing factors were cognitive function, occupational class, self-rated health, anxiety and emotional stability. In light of these findings, elderly people diagnosed with dementia and have a declining cognitive function and neuropsychiatric symptoms (Kales, et al., 2015), can therefore pose a higher risk of poorly managing the COVID-19 situation.

Research also shows that COVID-19 can actually heighten the symptoms of dementia. For instance, a study conducted through an international survey (Germany, Spain, the Netherlands and Australia) revealed that neuropsychiatric symptoms such as depression, apathy, delusions, anxiety, irritability and agitation were observed to worsen during the pandemic (Wei, et al., 2022). This was due to limited understanding of the situation and not living with the caregiver. The study did not mention where the users with dementia «live», if they were in institutions or home-dwelling, but the number of participants who did not live together with their family members with dementia was shown in the demographics. And as mentioned, not living with the caregiver was one of the factors that was shown to worsen the symptoms of dementia. Furthermore, the study put on view the psychological impacts not just to patients with dementia but to their carers as well. Carers reported experiencing a decline in their own mental health due to increased stress, limited social networks, uncertainty about the future, and loneliness.

In a study administered in Canada where 417 people participated (395 of which were relatives and 22 were persons with dementia), it became evident that the pandemic increased the level of stress, with 89% of the relatives and 83% of the patients reporting that they felt lonelier and isolated after

the onset of the COVID-19 pandemic (Tam, et al., 2021). Participants also detailed their use of technological devices which gave them a chance to communicate with their family members at least twice a week. However, they also revealed the technical problems and issues with privacy and data security associated with it. In the study, the participants' living situation, whether in long-term facility or at home, was not specified in the text nor included in the inclusion criteria.

A study with home as the context was conducted in Norway by Rokstad, et al. in 2021, examining the experiences of the spouses of people with dementia during the COVID-19 pandemic. Findings show that some of the factors that caused the aforementioned undesirable effects of COVID-19 to the psychosocial well-being of patients and caregivers were the discontinuation of services, and the restrictions on social gatherings and/or visitations. The respondents also revealed their coping mechanisms against the radical changes imposed during the pandemic, emphasizing the importance of personal initiatives to seek out nature, for example, or to do physical exercises.

Surprisingly, two other factors that had contributed to the negative impacts on psychosocial health was the use of protective gears and restricted time for home care workers to carry out their tasks. An international study (United Kingdom, Spain, Ireland, Italy, Australia, USA, India, Kenya and Brazil) concluded that healthcare workers had difficulty in implementing social distancing due to the high dependence on nursing and care of elderly people with dementia (Suarez-Gonzales, et al., 2020). In addition, elderly with dementia had more difficulty recognizing the humans/workers behind the facemasks and protective gears, leading to the lack of trust and ineffective communication between them and the healthcare workers. According to the study, this had required the healthcare workers to work harder, causing them to experience psychological, social and physiological problems in turn. This cross-country study included users with dementia living in nursing homes, confined in community hospitals, and home-dwelling.

Consequently, challenges on implementing infection control measures on the patientgroup were also recorded. Due to emergence of behavioural and psychological symptoms of dementia (BPSD), for example, "wandering", it became difficult to contain COVID-19 infected patients with dementia in isolation (Nkodo, et al., 2020). It also indicated that weakening cognition abilities resulted to difficulty in understanding or remembering the routines and protocols, hence resulting in deviations or non-compliance. In my experience as a nurse who had worked in isolation posts where elderly patients with dementia were usually confined, it became even more strenuous when the said patients were not assessed for independent decision-making capabilities. This often required an immediate

collaboration among the healthcare workers (doctors, nurses, caregivers, etc.) and other parties who had the power to decide for the patient (county doctor, closest relative), in order to provide continuity of treatment and nursing care.

These aforementioned findings from earlier research and general facts from science books and articles, together with my own work experiences and observations, clearly reveal that the COVID-19 pandemic had resulted to undesirable impacts on psychosocial well-being. However, an earlier study conducted in four Norwegian municipalities found out that, in general, healthcare workers had the tendency to prioritize bodily or physical needs over the psychosocial needs of home-dwelling elderly with dementia (Hansen, et al., 2017). Conclusions made by the authors revolved around the need for conceptualizing psychosocial needs and clarifying which entities should be responsible in meeting those needs. In relation to this, I would like to examine if those findings and conclusion had been actual during the COVID-19 pandemic. Investigating this topic can help gain a better understanding of how home care workers managed the said needs within their own context, while undergoing challenges brought about by a global pandemic.

1.3 Purpose of the study

The COVID-19 pandemic had had a great impact on the psychosocial well-being of home-dwelling elderly with dementia. The focus of this study is to raise awareness on the experiences of homecare workers, the challenges and opportunities they met, in managing the psychosocial needs of this user group. My hope is that this thesis will prove itself relevant and beneficial to geriatric healthcare, which emphasizes the need for a bigger understanding on the aging process, the resources of older persons, their life stages and living conditions within a diverse society (USN, 2023). Findings can also contribute to ensuring the quality of home care services being rendered to home-dwelling elderly persons with dementia, in support of the government reform *Leve hele livet*, which aims to provide the elderly “the opportunity to live at home for as long as possible and receive support to manage each day, in spite of medical diagnoses and dysfunctionality” (Meld. St. 15, 2017-2018, s.121).

1.4 Thesis question

This study aims to answer the following research question and subquestions:

Which experiences did healthcare workers have in managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia during the corona pandemic?

1.4.1 Subquestions

- a. What concrete measures did healthcare workers do to meet the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia?
- b. Which adjustments or adaptations were made?
- d. How can these experiences be used to improve psychosocial healthcare towards elderly patients with dementia?

1.4.2 Key terms

A short description of key terms is presented in this section. A more detailed description of each concept can be found in the next chapter, Theoretical perspectives (p.15).

Dementia

Dementia is a collective term for several chronic diseases that affect the brain (Helse- og omsorgsdepartementet/HOD, 2021, p. 6). In addition to cognitive failure, a person with dementia can experience behavioral and psychological symptoms of dementia (BPSD), also called neuropsychiatric symptoms, which can manifest as agitation, depression, apathy, repetitive questioning, psychosis, aggression, sleep problems, wandering and other inappropriate behaviors (Kales, et al., 2015). According to the Norwegian National Center for Ageing and Health (Nasjonalt senter for aldring og helse, 2020), 101, 118 inhabitants or 1.88% of the population of Norway have dementia. Around 99,000 of them belong to the age group 65 and above.

Coronavirus disease / COVID-19

The World Health Organization (WHO, n.d.) defines COVID-19 as “an infectious disease caused by the SARS-CoV-2 virus”. It can produce mild to moderate respiratory illness which many healthy people can recover from in a few days without further treatment. However, the disease can be deadly for people with weakened immune system, old age, and underlying medical conditions like cardiovascular diseases, diabetes, cancer or chronic respiratory diseases (WHO, n.d.).

Psychosocial needs

Psychosocial needs must be met in order to achieve psychosocial well-being. Stubberud (2019, p.18) describes psychosocial needs as necessities that has something to do “with the person’s psyche, that is, the spiritual or the mental” (p. 16-18). It can also be categorized into two areas: 1) the emotional needs, which covers the patient’s experiences of being sick or ill,

his/her history and reactions, and 2) the relational needs, which covers the need for company, contact and support from other people (Ehrenberg, et al, 1996). Maslow (1943) ranked psychological needs on top of his 5-sets of goals or basic needs, with each of the needs building on each other. *Psychosocial well-being*, on the other hand, can refer to a person's «quality of life», and involves emotional, social and physical components (Eiroa-Orosa, 2020, p.1).

Home-based care in Norway

The Norwegian welfare state system is comprehensive and guarantees help to its citizens when they need them, regardless of social status or income (Christensen & Berg, 2022). It covers an array of public schemes, which includes health and care services. The municipality has the task of reviewing the applications and evaluating the user's needs, and determining if they could be managed at home (The Health and Care Services Act - hol, 2011, §3-2). Home healthcare services in Norway include home nursing and other services that can be performed in the patient's home, like rehabilitation, occupational therapy and mental healthcare. Physiotherapy is also offered, but the patient should shoulder a user fee.

1.5 Scope and delimitation

This study focuses on the experiences of home care workers in managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia. The scope of this study is limited to recruiting at least 6-8 home care workers within 1-2 municipalities in South-eastern Norway, preferably with experience/s in managing COVID-19 isolated elderly with dementia during the coronavirus pandemic (between 2020-2022) in the country. Focus group interview (FGI) is used in data-gathering, and thematic analysis in analyzing the results. The study is conducted between August 2022 - May 2023. Recruitment and FGIs were carried out between August - September 2022.

This study will not focus on the severity of the dementia diagnosis, nor the living situation of the patients (living alone, living with other people, living in private homes, living in communal settlements, etc.). Comorbidities, use of alcohol and/or other illegal substances, and disabilities are also not going to be the focus. The patientgroup in the study will refer to home-dwelling elderly with dementia, aged 65 and above, who were infected with COVID-19 and were in isolation for a period of time.

1.6 Structure of the thesis

This thesis consists of six (6) chapters. Chapter 1 introduces the topic, the research question and subquestions, and gives a review of previous research. Chapter 2 presents the theoretical framework. Chapter 3 provides a detailed account of the methodology, its strengths and limitations, and ethical considerations. Findings are presented in Chapter 4, and Chapter 5 provides a discussion of the results generated using thematic analysis. Chapter 6 concludes the study.

2 Theoretical framework

According to Larsen & Adu (2021, p.124), a theory is “a statement or a group of statements that contains key concepts (themes) and relationships between them”, which use or presence has been systematically examined in situations, events, experiences and/or processes. A concept, meanwhile, is an idea, or a theme deducted from data (Larsen & Adu, 2021, p.125). Theoretical framework in research consists of key concepts, models, constructs, and/or theories, with the purpose of “linking what a researcher plans to do (or is doing) to what has been done” (Larsen & Adu, 2021, p.127). In other words, the theoretical framework connects the existing knowledge of abstract ideas to the actual research question. It can be used as a perspective to gain a better understanding of the participants’ experiences and can function in “explaining the study, representing the study, justifying the study, informing the study, or viewing the study” (Larsen & Adu, 2021, p.130-135).

The following key concepts and theoretical perspective served as foundations for this study. It gave me a point of reference to which the study should focus on, that is, managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia during the coronavirus pandemic. Furthermore, they provide a backbone of knowledge which helped me gain a better understanding of the topic in question, guiding me through data analysis, and discussion of the research findings. The key concepts were selected for the reason that knowledge about dementia, with its wide array of symptoms, and COVID-19 infection control measures can be relevant in providing person-centered psychosocial healthcare to the patientgroup. This knowledge can also be relevant in assessing why providing person-centered healthcare could be challenging.

Two concepts: dementia in older people and COVID-19 pandemic and infection control, were first presented. A main theoretical perspective, person-centered care, and an associated concept, psychosocial well-being, followed. However, the order of presentation does not equate to the importance of each key concept and theory. Each is significant for the entire process.

2.1.1 Dementia in older people

Dementia as a diagnosis was briefly defined under Key terms (1.4.2, p.14). In addition to cognitive decline, people with dementia can show symptoms of behavioral and psychological distress or BSPD, also called neuropsychiatric symptoms, which can manifest as feeling of depression and withdrawal, anxiety and disaster response, change in eating habits, delusions, hallucinations, apathy and lost of

interest, psychomotor agitation, irritability and aggressiveness, repetitive actions, yelling and clinging, and circadian rhythm disorders (Wyller, 2020, p. 277).

According to the World Health Organization (2023), dementia is a public health priority, affecting more than 55 million people globally, and the numbers are expected to increase with nearly 10 million new cases every year. Furthermore, 60-70% of cases can be attributed to Alzheimer's as the most prevalent type of dementia. WHO (2023) also identified dementia as the seventh leading cause of death among other diseases and the major reason for dependency and disability among the elderly people worldwide.

Projections of people with dementia in 2020, 2050, and 2100 in Norway

	Year 2020	Year 2050	Year 2100	Ratio 2050/2020	Ratio 2100/2020
Total					
30-64	2,108	2,203	2,095	1.0	1.0
65-69	2,008	2,383	2,489	1.2	1.2
70-74	14,493	17,153	18,277	1.2	1.3
75-79	16,691	29,774	29,512	1.8	1.8
80-84	20,380	49,866	55,267	2.4	2.7
85-89	23,675	64,498	97,093	2.7	4.1
90+	21,762	70,912	175,402	3.3	8.1
Overall	101,118	236,789	380,134	2.3	3.8
Men					
30-64	1,057	1,106	1,055	1.0	1.0
65-69	783	936	999	1.2	1.3
70-74	8,140	9,748	10,568	1.2	1.3
75-79	8,349	15,544	15,788	1.9	1.9
80-84	8,814	24,202	27,870	2.7	3.2
85-89	8,370	28,290	45,520	3.4	5.4
90+	5,567	25,406	70,805	4.6	12.7
Overall	41,080	105,233	172,605	2.6	4.2
Women					
30-64	1,051	1,096	1,040	1.0	1.0
65-69	1,225	1,447	1,490	1.2	1.2

Projections based on population estimates by gender from Statistics Norway (main alternative).

Figure 1. Projections of people with dementia in 2020, 2050, and 2100 in Norway. From "Current and future prevalence estimated of mild cognitive impairment, dementia, and its subtypes in a population-based sample of people 70 years and older in Norway: The HUNT study" by Gjøra, et al. (2021), *Journal of Alzheimer's Disease*, 2021, 79(3): 1213-1226. doi: 10.3233/JAD-201275

In Norway, a study on the prevalence of dementia conducted in 2020 by the Norwegian National Center for Ageing and Health (*Nasjonalt kompetansetjeneste for aldring og helse*) revealed that 14,6% of its population aged 70 years and above have dementia (HOD, 2021, p.8). Figure 1 shows that the number of dementia cases is expected to climb up from 101,118 in 2020 to 236, 789 by 2050. This staggering information could mean a heavier load for the healthcare system and the caregivers.

The World Dementia Council (WDC, 2018, p.29) reported that this global health issue could lead to financial ruin, if not acted upon by enforcing all interventions to prevent dementia. A recent study estimated that the global cost of Alzheimer’s disease and related dementias (ADRD) would skyrocket from \$2.8 trillion in 2019 to \$16.9 trillion in 2050 (Nandi, et al., 2022).

Consequently, research on dementia prevention has been flourishing in current years. For example, in an extensive research carried out by the Lancet Commission (Livingston, et al., 2017, 2020), as much as 40% of potential risk factors to developing dementia appeared to be modifiable, mainly by reducing neuropathological damage and increasing and maintaining cognitive reserve. Specific preventive measures that can be done are: minimizing diabetes, treating hypertension, preventing head injuries, quitting smoking, reducing air pollution, reducing midlife obesity, maintaining frequent exercise, reducing occurrence of depression, avoiding excessive alcohol, treating hearing impairment, maintaining frequent social contact and attaining high level of education. Thusly, focus on the psychosocial well-being can help prevent or slow down the onset of dementia.

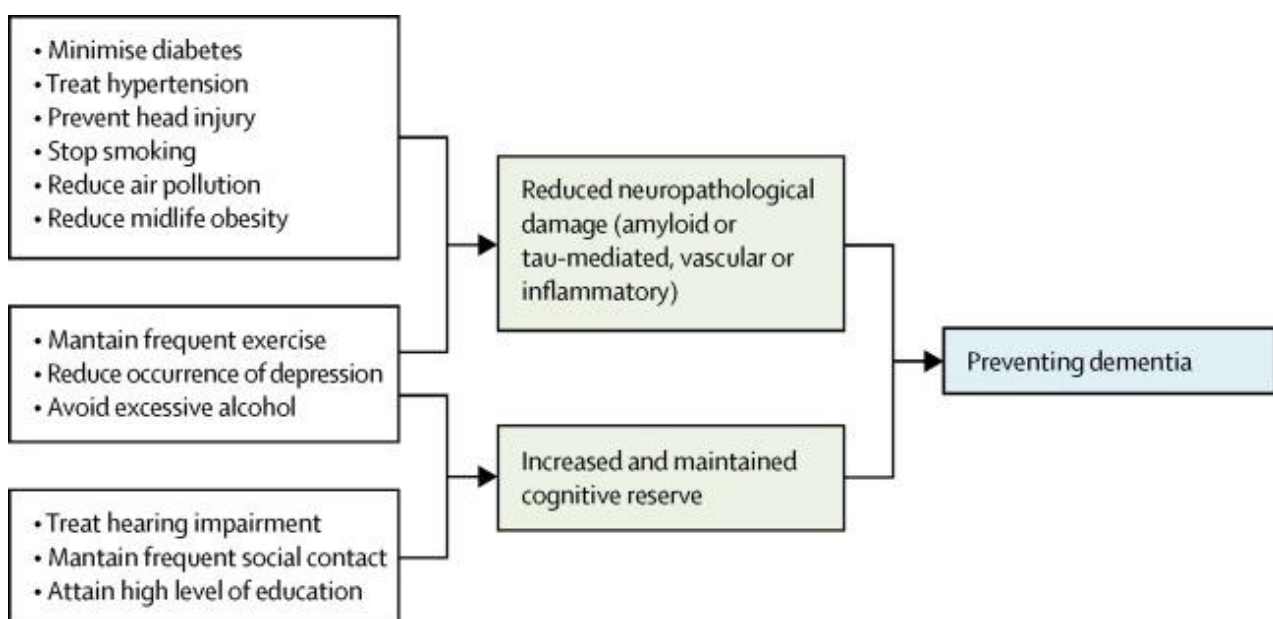


Figure 2. Possible brain mechanisms for enhancing or maintaining cognitive reserve and risk reduction of potentially midifiable risk factors in dementia. From “Dementia prevention, intervention, and care: 2020 report of the Lancet Commission” by Livingston, et al. (2020). *The Lancet Commissions*, 396(10248): 413-446. doi: 10.1016/S0140-6736(20)30367-6

2.1.2 COVID-19 pandemic and infection control

COVID-19 as a respiratory disease caused by the corona virus (SARS CoV-2) was defined in Key Terms (1.4.2, p.14). Infection control measures have been implemented by different countries worldwide since WHO declared it as a global pandemic in March 2020 (WHO, n.d.). As of 3 May 2023, more than 765 million cases were registered worldwide, with over 6 million deaths. In Europe, the number of registered cases has exceeded 275 million, with approximately 2.2 million deaths (WHO, n.d.).

Infection prevention and control can be defined as “a practical, evidence-based approach which prevents patients and health workers from being harmed by avoidable infection as a result of antimicrobial resistance” (WHO, n.d.). Infection prevention encompasses all systematic measures which could prevent the spread of infection within a population, including vaccination and tracking (Stordalen, 2022, p.24). In Norway, infection prevention and control is regulated by The Infection Control Act of 1994 and incorporating regulations.

In line with the increasing outbreaks of COVID-19 infection, the Norwegian Directorate of Health (*Helsedirektoratet*) released national guidelines for managing the coronavirus pandemic, entitled Coronavirus – decisions and recommendations (*Koronavirus – beslutninger og anbefalinger*), first published in 2020 and last updated in March 2023. According to the guidelines, municipal healthcare should create and implement procedures for observation and treatment of home-dwelling users who are infected by the coronavirus, in order to secure that both the users and their relatives receive responsible and professional follow-ups at home, in view of possible rapid development or worsening of the disease. It is also recommended that implementation of infection control measures be well-adjusted in the best way possible to the needs of patients with cognitive failure and/or dementia (NIPH, 2022).

In December 2020, mRNA COVID-19 vaccines made by Pfizer-BioNTech and Moderna were given emergency use authorization by the U.S. Food and Drug Administration (FDA) (US Department of Health and Human Services; HHS, 2022). Since then, more than 13 billion vaccine doses were administered globally (WHO, 2023). In Norway, over 12 million doses were already given as of April 2023 (NIPH, 2023).

As mentioned, both international and local organizations work hand in hand to stop COVID-19. In Norway, local authorities, like the Directorate of Health and the Institute of Public Health, were entrusted with overseeing the management of the coronavirus pandemic in administrative level, releasing manuals and guidelines for local bodies to implement. Healthcare workers in hospitals and

municipal healthcare facilities had to update themselves on these guidelines throughout the pandemic, in addition to adhering to basic laws on healthcare, like the Health and Care Services Act (2011), the Infection Control Act (1994), and the Patient and User Right Act (1999), as well as the Code of Ethics for each healthcare profession. These are some matters to consider when discussing how healthcare workers addressed the needs for person-centered psychosocial healthcare in the midst of a pandemic.

2.1.3 Psychosocial well-being and person-centered care

Nursing care has strived to provide holistic care throughout the years. Holistic care refers to both the patient's physical and psychological, emotional, and spiritual needs (Jasemi, et al., (2017). It has its roots in the concept of holism, which came from the Greek word, *holos*, meaning "whole", and advances the idea that "the whole is greater than the sum of its parts, and that the mind and spirit have an effect on the body" (Keegan, 1987, p.499). Since its popularity in nursing research and history, nursing interventions have been calibrated to shed more light to the patient's psychosocial needs, parallel to the basic bodily needs.

Meeting a person's psychosocial needs can promote *psychosocial well-being*, which refers to one's «quality of life» and involves emotional, social and physical components (Eiroa-Orosa, 2020, p.1). Psychosocial needs may refer to the necessities associated with the person's psyche, or spritual and mental needs, and are based on how a person experiences the state of being sick or ill (Stubberud, 2019, p. 16). Needless to say, these needs are subjective and can be categorized into the emotional and relational aspects (Ehrenberg, et al., 1996).

Nursing care can be a challenging job when it comes to understanding what psychosocial needs mean for each individual. Thus, it is of great importance to bear person-centered care in mind, for the reason that each indivicual is unique and irreplaceable (Kristoffersen & Nortvedt, 2016, p. 101). This means that nurses are expected to cater to individual preferences and the things that define psychosocial well-being for each user. The Nursing Code of Ethics 1.10 emphasizes that nurses should "provide evidence-informed, person-centered care, recognizing and using the values and principles of primary health care and health promotion across the lifespan" (ICN - International Council of Nurses, 2021, p.8).

Person-centered care is a philosophical approach developed by the English social psychologist Tom Kitwood (1937-1998) in 1997 centering on the maintainance and nurture of the *personhood* to a

person with dementia. It takes into consideration the person's experiences of the situation and the world around him/her, which may be influenced by his/her personality, life history, physical health, symptoms of dementia, and social environment, and thus requires modifying care to fit the person's perspectives (Nasjonalt senter for aldring og helse, n.d.). Elderly persons with dementia can suffer from communication problems, making it difficult to express their needs and wants. However, Kitwood (1997) claims that everyone has basic psychosocial needs, namely, the need for identity, love, comfort, occupation, inclusion and attachment. These basic psychosocial needs could lay the foundation for psychosocial health management for users with dementia,.

Several tools and frameworks have been developed to help with the implementation of person-centered care for persons with dementia, such as the VIPS modell developed by Dawn Brooker in 2007. VIPS stands for value people, individual's needs, perspective of service user and supportive social psychology. Another example is The Marte Meo method, which uses video recordings to process interactions between healthcare worker and users, developed by Maria Aarts in the 1970s (Marte Meo International, n.d.). Lastly, the structured environmental treatment (*strukturert miljøbehandling*) is an individualized plan, directed towards empowerment and user codetermination (Røen & Storlien, 2015). It promotes the feeling of security (patient safety, shielding, setting boundaries, management of physiological and medical needs), support, social and physical structure, engagement based on previous interests and ability to cope, and acknowledgement of the patient's identity (Nasjonalt senter for aldring og helse, n.d.). The method consists of lectures about dementia (its symptoms, charting, person-centered care and environmental treatment) and action planning tools, like individualized treatment plan, daily routines, and daily division of tasks.

3 Methodology

In this chapter, I will present in detail the research process that was undertaken in order to gather the necessary data, the challenges met in acquiring the said data, and the ethical considerations. It is important to create a strategy for the research process to ensure that the study will be feasible, reliable and valid (Leseth & Tellmann, 2014, p.41). It can also help in structuralizing the process of gathering and processing information. It is also important to note that the project description (*Prosjektbeskrivelse*, from the course MPRO300) which was submitted prior to the research study served as a guide, and thusly, I used some important texts and ideas from the said unpublished material (e.g., some of the literature background, which methodology to use, and the ethical considerations).

The study is qualitative in nature, with hermeneutic approach to interpretation, and following an explorative and descriptive design. Focus group interview (FGI) was chosen as method for data gathering. Afterwards, acquired information was subjected into thematic analysis, narrowing the extensive interview responses down into specific themes to serve as main points for discussion. Throughout the data collection process, I maintained a log to note down important details and progress towards the completion of the study.

3.1 A qualitative study

This study utilizes a qualitative research methodology with explorative and descriptive design. For the reason that this study will examine a topic revolving on other people's subjective experiences, a qualitative approach is deemed relevant and suitable. Qualitative research, according to Dalland (2020, p.54), is appropriate when the purpose of the study is to capture opinions and experiences which cannot be measured or quantified. In other words, the knowledge that can come out from a qualitative research is not naturally given or objective, but is created by immersing one's self in the particular field that is being studied (Leseth & Tellmann, 2014, p.22). Furthermore, the methodology is applicable when one aspires to find meaning, significance and nuances in events and behavior, in order to strengthen one's understanding of why humans behave as they do (Malterud, 2017, p. 31).

3.1.1 Explorative and descriptive design

This study uses an explorative and descriptive design. Qualitative descriptive research presents a transparent description of the participants' experiences of a topic (Doyle, et al., 2020, p.444-445).

While descriptive design documents and describes a phenomenon through the use of the subjects' perspectives, explorative design provides an opportunity to develop a new knowledge about a topic to which there is little or inadequate amount of information (Stebbins, 2001, p.6). In order to explore a topic effectively, Stebbins (2001, p.8) advised researchers to practice flexibility and open-mindedness.

In this regard, I used purposive sampling in recruiting informants, focus group interview for data collection, and thematic analysis for analysis and interpretation. These are techniques generally used in this type of qualitative research (Doyle, et al., 2020, p. 446-448).

3.1.2 Hermeneutic approach

The word 'hermeneutic' is often acquainted with the name of the Greek messenger god *Hermes*, who bore knowledge and understanding between the gods and mortals (Paterson & Higgs, 2005, p. 342). One of Hermes' well-known attributes was his lingual eloquence (Britannica, 2023). In philosophy, however, the term hermeneutics refers to «the study of the methodological principles of interpretation», and was exercised mainly on biblical texts in earlier times (Merriam-Webster Dictionary, n.d.).

I incorporated the hermeneutic approach in this study, as advocated by the German philosopher Hans-Georg Gadamer (1900-2002). He believed that researchers need to acknowledge their biases and prejudices or pre-judgments as part of the interpretive process (Paterson & Higgs, 2005, p.342). Gadamer proposed that a fusion of horizons (i.e., the historical horizon of the past and the present horizon) happens as the researcher tries to understand the study findings. Hence, the familiar and the unfamiliar become merged and connected in the process (Paterson & Higgs, 2005, p.342-344). In this study, my background as a healthcare worker with experience in isolating and treating COVID-19 patients in hospitals and local acute facilities facilitated my understanding of the research findings and how others experienced the phenomenon. However, I was aware that home care is another context and that other factors might have played a role in how the participants experienced the pandemic.

There are several propositions to how a hermeneutic approach can be carried out in textual analysis. However, I chose to follow the Gadamerian metaphor of fusion of horizons in this study, where «different interpretations of the phenomenon under investigation are brought together through dialogue to produce shared understanding» (Paterson & Higgs, 2005, p.343). During the data analysis,

continuous reflection and conversation between the text and the author through thematic analysis, as proposed by Braun & Clarke (2022), composed the *hermeneutic spiral* that is described by the interpretation of dissected parts of the text and interpretations of the whole study (Paterson & Higgs, 2005, p.344).

3.2 Data Collection

3.2.1 Recruitment and selection of participants

Purposive sampling was used as a strategic method for recruitment in this study, which means choosing participants who can give the most valuable information about the subject (Leseth & Tellmann, 2014, p.54). In other words, it was made a prerequisite that informants have had previous knowledge and experience in the area. I had to determine whether to go *bottom-up*, where I ask possible participants directly from my network as a healthcare worker, or *top-down*, meaning, seeking engagement with help from the administrative level. I opted to go with the latter and created a log of the phone and e-mail conversations throughout the process.

Conducting the study in the public home care system of one of the bigger municipalities in south-eastern Norway was the original plan. The goal was to recruit 6-8 healthcare workers from two home care units in the same district, and conduct a 2-hour FGI on the subject matter. However, due to minimal capacity in terms of human resources and time on the part of the said municipality, I decided to extend the invitation to two smaller municipalities. I received a positive response from one of them. For the purpose of this study, the bigger municipality will be referred to as "Municipality A" and the smaller one as "Municipality B". The other smaller municipality which did not partake in the study will be referred to as "Municipality C".

Municipality A consists of more than 10 home care units or bases. Each unit is led by the unit manager (*avdelingsleder*). The institution manager (*virksomhetsleder*), meanwhile, supervises 4-8 units. Getting in touch with the unit managers proved to be a challenging task. Some of the names and telephone numbers on the official website were outdated. In addition, some units were in the process of getting a new manager, or that the manager was on leave-of-absence (LOA) for a period of time. Because of this, I decided to go a notch further and contacted the institution managers, who were very helpful and provided e-mail addresses and contact numbers of the current unit managers. They also gave me permission to book and use meeting rooms in two of the home care units, so it would be easier for possible informants to participate in the interviews.

Municipality B has more than 3 home care units, with each sending forth 1-2 participants. A unit manager also helped arranged the time and venue. Unfortunately, Municipality C, which also has more than 3 home care units, declined the invitation due to other research studies being conducted in their units.

3.2.1.1 Inclusion criteria

Meeting the patient's psychosocial needs is usually understood to be a «common responsibility» (*felles ansvar*) for each and every one working in healthcare. According to the Quality regulations for nursing and care services (*Kvalitetsforskriften for pleie- og omsorgstjenestene*, 2003, §3), the municipal health care should lay out written procedures on managing the users' basic needs, including the need for psychosocial well-being and the opportunity to independently care for one's self. Furthermore, healthcare services should cater to the individual needs of users with dementia and users who have difficulty expressing their needs, and offer customized and varied activities which could promote positive experiences like mutual respect, certainty and security, independence and management of one's own life, social interaction and companionship with others.

In line with this, I chose to include any registered or authorized healthcare personell (nurses, nursing assistants, social workers, and others) who fulfill the following inclusion criteria:

- Registered / authorized personnel working in municipal home care system (nurses, nursing assistants, health workers, social workers, etc.)
- Has/had experience treating or working with COVID-19 isolated home-dwelling elderly people with dementia
- Has *fast turnus* or permanent working schedule (minimum 50% position), for continuity
- Can speak Norwegian or English language

Figure 3. Inclusion criteria.

In total, nine (9) home care workers (5 nurses, 2 nursing assistants, 1 healthcare worker and 1 care assistant) from seven (7) home care units within two municipalities in South-eastern Norway participated in a series of three focus group interviews (FGIs). There was no age, gender or racial preference. However, as a female-dominated occupational group, all the participants who managed to take part in the FGIs were women aged 26-59 years old.

Participant , age	Occupation	% position (<i>pr. stilling</i>)
F, 40s	Reg. Nurse	100%
F, 30s	Reg. Nurse	100%
F, 20s	Reg. Nurse	100%
F, 20s	Reg. Nurse	100%
F, ?	Reg. Nurse	100%
F, 50s	Nursing assistant	100%
F, 50s	Nursing assistant	75%
F, ?	Healthcare worker	100%
F, ?	Care assistant	70%

Table 1. Participant demographics.

3.2.2 Focus Group Interviews (FGIs)

Focus group interview (FGI) was chosen as method for data-gathering for the reason that is best suited for studies which aim to “learn about experiences, attitudes or points of view in environments where many people interact/collaborate” (Malterud, 2017, p.138). Through this method, participants can compare and/or align their own experiences with that of others, possibly providing the researcher an understanding of the participants’ experiences and opinions in the process (Morgan, 1998, s.11). Moreover, FGI can help the participants in brainstorming for new measures which can improve a field of speciality, such as home care services, by extracting diverse opinions and beliefs and assessments of the actual topic (Leseth & Tellmann, 2014, p.89).

Nonetheless, FGI is a rational method which can require minimal resources (Malterud, 2017, p. 140). Given a limited amount of time and resources for this study, I chose FGI, hoping that it can provide a substantial amount of data within a confined period of time.

However, like other research methods, certain limitations can happen when conducting an FGI. For instance, one can face challenges connected to recruiting the desired number of participants. There is also the management of the interview itself, where it might be difficult to control the flow of the discussion. For the reason that informants will be coming from different backgrounds and age-bracket, asymmetry or power imbalance can occur and affect the openness and engagement of each

participant (Halvorsen & Jerpseth, 2019, p.9). Therefore, it is important to conduct the FGI in a pleasant and relaxed environment, to remind each and every one to show respect, and to clarify the roles of each person in advance.

Normally, an FGI should consist of 4-6 members with similar background and experiences (Lerdal & Karlsson, 2008, p.5). However, alterations can be made depending on the capacity and availability of resources. According to Cortini, et al. (2019), focus groups can be classified in dyads, triads, mini-groups and full-groups (with more than 7 participants). The number of participants can affect the quality of the data material during brainstorming, in what the writers referred to as the “blocking effect”, where lesser amount of ideas are generated when the group is large (Cortini, et al., 2019, p.30). The writers also pointed out that having a triologue or a mini-group can promote conversational unity, and can save the author from a conspicuous work during the analysis phase. The important thing to emphasize is that the choice of number should reflect the need of the topic or subject matter and the availability of resources (Cortini, et al., 2019, p.38).

In this study, three mini-FGIs a’ 1-1.5 hour were conducted: two in Municipality A and one in Municipality B. Each mini-FGI consisted of 3 participants. I served as the moderator, which had the role of guiding the group discussion, but not participating in it (Morgan, 1998, p.1). Norwegian language, as the occupational language, was used during the FGIs.

Municipality A

Upon reaching the desired number of confirmed participants (8 in total) and agreeing on the meeting time and place, the first FGI was conducted. An e-mail reminder was sent out to the participants in advance. Nonetheless, only three (3) showed up due to unforeseen circumstances (absence due to sickness, reconsidered by the manager due to high pressure for manpower at work, and forgetting about the interview). The three participants came from 2 different home care units.

Another FGI was scheduled, with three confirmed participants from two home care units. In total, six (6) participants from four (4) home care units shared their experiences on the topic via mini-FGIs. Both interviews were held in spacious meeting rooms where refreshments were served to create a pleasant ambiance conducive to discussions and exchange of ideas.

Municipality B

Four (4) participants from four (4) home care units within Municipality B confirmed attendance. On the day itself, one (1) was not able to partake. The mini-FGI was held in a spacious room and refreshments were also served.

	No. of participants	Home care unit
FGI 1	2	a
Municipality A	1	b
FGI 2	2	c
Municipality A	1	d
FGI 3	1	e
Municipality B	1	f
	1	g
Total	9 participants	7 units

Table 2. Focus group interviews conducted.

A powerpoint presentation was used in the FGIs, containing the research topic, how FGI was to be conducted, and the guide questions (see Annex 1, p.82).

3.2.2.1 Use of interviewguide

At the beginning of the FGI, the participants were reminded to be «open», and that they were permitted to throw questions amongst each other. Follow-up questions were also encouraged. They were also informed that I, as the moderator, was there to aid the discussion, keeping its flow and jotting down some notes for summarizing purposes, but that I would not be participating. I would also be redirecting them back to the topic, if diversions happen.

To help guide the discussion, interview questions were devised (see Appendix C, p.75). According to Krueger (1998, p.11), the use of an interviewguide can save time and can promote more enthusiasm and spontaneity. The guide questions were basically borrowed from the research question and sub-questions, with the possibility of having follow-up questions if new, but relevant, topics emerge in

the process. This means that the FGIs were performed semi-structurally. After the first FGI, the questions were reviewed to check if they needed to be revised or modified. Some clarifications, for example, the scope of the study and the use of conceptual terms like person-centered care and psychosocial well-being, were also incorporated, based on input given by the first group.

As the moderator, I had to be flexible, as there had been tendencies for the group to tackle the questions in no particular order, leading to some repetitions and redundancy. This was caused by them not knowing all the questions (i.e., participants started to talk about the next topic before the question was shown to them). In the final FGI, I decided to show all the questions briefly in advance to give the participants time to reflect and to have an overview of the whole agenda, and thus, avoiding repetitions in the process.

Based on this experience, I found the use of an interviewguide effective in maintaining the flow of the conversation and in achieving coherence in an FGI. In addition, in view of the fact that the participants came from various life backgrounds and can have differing opinions, in spite of having a similar work milieu, the use of the interviewguide had helped keep them focused on the topic.

Lastly, it helped filter out the data which were irrelevant to the study.

3.2.3 Transcription

According to Green, et al. (1997, p. 172), a transcript is a text that represents an event, but that it is not the event itself. A transcript, in other words, is more than just words put on paper, but consists of data constructed for a particular purpose. In my case, I listened to the audio files first before transcribing them. As this was my first time to transcribe a substantial amount of data, I wanted to make sure that I had an understanding of the context and an idea of how the interview discussions flowed from topic to topic before actually transforming them into written text.

As someone who learns better through writing, I decided to transcribe the 3.25 hour-long audio files manually, that is, without the help of transcription softwares. Initially, the spoken words were transcribed word-per-word, without any in-depth interpretation or analysis of what was said. I did not omit sounds, like laughter or silence, from the transcription, as they help paint a picture of how the discussion went. However, I anonymized the transcription along way and censored sensitive topics which were irrelevant or did not answer the research question/s. The transcription consists of 96 pages in total.

The transcription was then translated from Norwegian to English. Then, I re-read and checked it multiple times for revision. The translation process is further described under section 3, Strengths and limitations, 3.7.2 Translation process and analysis, p.37.

3.3 Analysis

This research study utilizes Virginia Braun and Victoria Clarke's method for analysis, commonly referred to as thematic analysis (TA). TA consists of 6 phases which guide the researcher into interpreting the data on hand. The book (also available as a webpage), *Thematic Analysis: A practical guide* (Braun & Clarke, 2022), was used extensively. Braun and Clarke's method was chosen because it resonates with the methodological approach of this qualitative research study.

Thematic analysis highlights the need for *reflexivity*, meaning, that the "researcher's positioning inevitably shapes their research and engagement with data" (Braun & Clarke, 2022, p.14). The whole aspect of reflexivity also resonates with the definition of an explorative and descriptive research design, as outlined in Chapter 3, 3.1.1, p.22-23. Within and during the whole process, in spite of keeping myself open-minded and flexible to new knowledge that could emerge, my personal, functional and disciplinary subjectivity could have had an influence on the interpretation of the data. However, this awareness helped me to remember that the goal was to use that subjectivity to throw critical questions and commit myself in an ongoing process of reflection. My background in healthcare, particularly in geriatric healthcare and the implementation of infection control measures, served as an aid to positioning and routinary reflection, which could facilitate qualitative sensibility.

According to Brown & Clarke (2022, p.7), qualitative sensibility is showing interest in process and meaning, and nurturing the fact that controlling research bias or objectivity has no place in a reflexive TA. Instead of eliminating the author's perspective and assumptions in interpreting the data, the author embraces her position in the whole process and uses it to routinely reflect and throw critical and analytical questions about the subject matter. Hence, this process within thematic analysis can aid in developing a better understanding of the topic and is also in line with the concept of hermeneutics.

The research questions guided the entire analysis, from familiarizing with the data to developing and finalizing the chosen themes.

Familiarizing with the dataset

During the initial phase, I read and re-read the transcription several times while jotting down notes on possible points for analytical interpretation in red ink. During this process, I was already pre-analyzing the transcription in relation to the research questions. I experienced familiarizing with the dataset as looking at the interviewees' statements with a different eye every time.

Looking at some of the lines, I searched for hidden meanings and pondered on what was implied. Braun & Clarke (2022, p.35) emphasized that interpretation of meaning can have a range of levels, from explicit or surface meanings (*semantic*) to the more conceptual or implicit (*latent*). Looking at the data in this way during the earliest interpretation stage had helped me prepare for the coding part.

As an example, when asked about the measures undertaken to manage the psychosocial needs of the users, one of the interviewees said: *“At døra var litt på gløtt. Så du kan fange opp hvis de må ha besøk (That the door was slightly ajar. So you can sense if they needed to get a visit).»* In the context of that statement, the interviewee seemed to refer not only to the physical act of letting the door stand slightly open, but to using one's instinct or clinical intuition to capture the user's needs from a distance, taking into consideration that home nursing care during the pandemic meant fewer visitations for most service providers.

I also indulged in the variety of answers coming from subjects with diverse backgrounds. While I had my own experiences on the subject matter, some of the responses led to unexplored viewpoints, specifically in home nursing care. Clarke & Braun (2022, p. 15) advised that the researcher should be mentally prepared to tackle uncertainty, as new and unexplored information comes to view. Homecare nurses, for instance, had to juggle responsibilities in both clinical nursing and organizational and administrative functions, while assistants and other healthcare workers seemed to be more focused on providing patient care while tending to their own personal and familial worries during the pandemic. This is among the striking points in the interviews.

Enumerating the striking points gave an overview of the the relevant and more important details that could be used in the next phase - coding. Here is a list of the notable points from the interviews:

- Among the challenges encountered by home care nurses in managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia are: the difficulty in explaining or informing the users and their relatives about infection control measures and the seriousness it entailed, managing the users' skepticism and resistance due to changing routines and protocols, communicative and medical barriers brought about by the use of personal protective equipment (PPE), and maintaining confidentiality.
- Respondents felt pressured in the workplace. It was difficult for many of them to prioritize, considering their own personal relationships and their own health.
- They described and narrated in detail their observations and experiences on how the users might have felt, including reactions like confusion, fear and panic, uncertainty, feeling isolated and lonely, embarrassment, shame (in some cultures), anxiety, feeling sicker, agitation and frustration, disturbed sleeping patterns, understimulation, refusal/resistance/skepticism, and the YOLO (You only live once) effect, where users intentionally ignored protocols and restrictions because of old age.
- Psychosocial needs seemed to have been forgotten and not prioritized during the pandemic. There were also varied answers as to who or which entity was responsible for it. There was an emphasis on the functionality of activity centers (*dagsentre*), and how shutting them down affected the users negatively. Phone consultations were highly used during the pandemic.
- Relatives were a big resource during the pandemic. They were described as solution-oriented, more participative and more understanding. However, they also met COVID-19 deniers. Some interviewees also expressed their dismay when no relatives were present, such that they had to take that role in the end.

Raw data: Striking points from the interviews

As the dataset was translated from Norwegian to English, this phase of familiarization in reflexive TA also gave me time and space to come up with better translations for important terms and expressions.

Coding

According to Brown & Clarke (2022, p. 53), the coding process is all about exploring the diversity of the dataset and determining patterns of meaning by using codes. After familiarizing with the dataset, I carefully selected all significant statements from the interviewees, narrowing down the data by use of the research questions. These pages were printed out on marginalized paper, allowing comments

and codes to be noted beside each statement. Striking words were highlighted, and commonality among the statements was determined.

Initially, semantic codes were identified using the exact word/s from a set of statements. For example, in this statement, the possible codes were highlighted:

1: *“The dialog was also affected when talking behind facemasks. It was difficult to hear. Communication was disturbed, like, one cannot read facial features and it sounded like we’re mumbling.. There were times when one had to write things down, but if the user had bad eyesight, they couldn’t read.. I remember it as a very big challenge.. It ate up a lot of time, just putting the equipment on and off, and one got worried, surely, “I must not infect anyone”. It was very stressful, really.”*

Later on, I came up with latent (implicit, conceptual) codes.

Data	Codes
<p>1: <i>“The dialog was also affected when talking behind facemasks. It was difficult to hear. Communication was disturbed, like, one cannot read facial features and it sounded like we’re mumbling.. There were times when one had to write things down, but if the user had bad eyesight, they couldn’t read.. I remember it as a very big challenge.. It ate up a lot of time, just putting the equipment on and off, and one got worried, surely, “I must not infect anyone”. It was very stressful, really.”</i></p>	<ul style="list-style-type: none"> - Communication behind PPE became ineffective - Need to come up with ways to communicate/Be solution-oriented - One challenge after another - Using PPEs took a lot of time / Lesser time to be with the user? - Stressful situation

Finding patterns amongst the statement was also a challenging task. I gathered all statements that had something to say about the use of PPE, and some of them contained ethical dilemmas, like having to take them off to perform tasks better and/or because users ignored them, unless they do so.

The same process was done for the rest of the statements. A difficult part in this phase was eventually choosing which statement/s best represent the ideas and can be used in the succeeding stages. Some codes were retracted from several statements to create meaning, such as experiencing ethical

dilemmas. It is also important to note that an FGI is more of a discussion than an interview. Hence, several statements from several people are needed to come up with the code/s.

For example, participants were discussing how use of PPE could have led to medical errors in this conversation:

1: «If one had those eyeglasses which fogs up, and there was much of that..»

2: «I had eyeglasses.. Breathe, and then, I saw nothing.»

3: «If one has to do injections or clean wounds, you won't see very much.»

2: «And if it has fogged up a little, so the insulin might, so (the user) might get overdosage and so I had to take it off. Yes.. I took no chances.»

In the example above, I couldn't highlight specific text/s per se. Codes were elicited through my own interpretation of the spoken words and the context. Codes derived from the conversation are Use of PPE can lead to medical error, and Ethical dilemma.

The raw data was initially very extensive, and dissecting / analyzing the statements was a rigorous process. The codes were categorized by mapping diagrams, guided by the research questions. Annex 2 and 3 on p.83-88 contain a table showing an excerpt from the coding process and mapping images, respectively.

Developing themes

When the coding process was finished, I proceeded to creating themes. Note, however, that while I was in the process of deriving codes from the interview statements, I was also already pre-developing possible themes, based on the present codes, in my mind. Developing themes involved three phases: creating initial themes, developing and reviewing the themes, and refining, defining and naming them. Clarke & Braun (2022) suggested that the writer use an ample amount of time for this process. During this stage, one shifts the analytic attention from codes to larger meaning patterns or themes.

First, I gathered or collated all the codes and wrote them in post-its. Afterwards, I grouped or clustered them according to similarity or context. The research questions also guided the categorization process. Initial themes were, thus, created by use of mapping.

A recurring code, for example, was *Ethical dilemma*. It was elicited from responses detailing issues on maintaining confidentiality within communal settlements, and following guidelines on distancing and use of PPE to meet the psychosocial needs of the users and avoiding medical or treatment errors.

It also came from reports on relatives who were COVID-19 deniers, and the choice of succumbing to the sense of duty and obligation more than protecting personal relationships and their personal health and safety. Based on these responses and the recurring code, *experiencing ethical dilemmas in meeting the psychosocial needs of the subject usergroup during the pandemic* was generated as one of the first eight (8) initial themes.

Another recurring code was Definition of psychosocial needs (for the respondent). It was elicited from responses describing the respondent's thoughts and understanding of the term. While several of them described it as an assignment of the activity center, a few identified it as having relationships or the fulfilment of the emotional need for safety, like feeling secured. One of them responded that psychosocial needs are subjective, something personal. Stemming from this responses, another initial theme was created, namely, that *home care workers had varying views and understanding of the term psychosocial needs*.

Braun & Clarke (2022) advise the researcher to avoid getting attached to the initial themes to make it easier to reorganize them, omitting or letting some of them go, or revising them in accordance to the original dataset. This was done accordingly, narrowing down the codes, rearranging them, compacting the dataset in the process and revising the initial themes into more encompassing ones. From eight (8) initial themes, I narrowed them down to three (3), following a series of developing and reviewing process.

The final step was refining, defining and naming the themes, which also proved to be a tedious and resource-intensive part. Not only was naming the themes challenging; it was also tough to select sub-themes to include. I wished to keep the whole essence of each theme with all the ideas and responses, while trying to concretize each of them at the same time. This process, although time-consuming to accomplish, was important for the research focus and substance. In the end, I concluded this phase with three major encompassing themes and a few subthemes. The table below gives an overview. Each theme and subtheme will be further explained in Chapter 4: Results.

Managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia during the coronavirus pandemic

<p>Home care workers had varying views and understanding of the term “psychosocial needs”, and whose responsibility its management was.</p> <ul style="list-style-type: none"> •From meeting relational needs, like having someone to talk to, to fulfilling emotional needs, like feeling secured, or that it is something personal •The responsibility falls under one of the following: Activity centers, Relatives, A collective responsibility, Administration and government, or that the respondents didn’t know 	<p>Healthcare workers met ethical dilemmas which affected the management of psychosocial needs during the pandemic.</p> <ul style="list-style-type: none"> •Committing deviations from guidelines and routines to meet users’ need for social companionship and physical nearness •Difficulty in implementing infection control measures, providing treatment and carrying out testing procedures due to scope and severity of the disease, prolonged use of PPE, and encountering COVID-19 deniers •The issue of confidentiality / lack of privacy in communal settlements •Felt pressured: Torn between the sense of duty and obligation and their own personal safety 	<p>Person-centered psychosocial healthcare required interpersonal and organizational skills and competence.</p> <ul style="list-style-type: none"> •Knowledge of dementia was crucial in analyzing changed behavior and coming up with creative solutions •Use of welfare technology and phone consultations •Prioritizing and advanced and careful planning, including collaboration with relatives and other healthcare professionals
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Table 3. An overview of the themes and sub-themes.

3.4 Strengths and limitations

3.4.1 Group size

The number of participants was carefully considered, although availability of resources was a deciding factor for all three FGIs. The group size is important to consider due to its effect on the group dynamics. During the entire recruitment process, the managers decided whether the unit, or a certain worker, despite signing the informed consent form, could come and participate in the research study. The managers expressed that they had to plan and decide in accordance to availability of time, financial and manpower resources. Even if a good length of time was provided in advance

(around 4 weeks from the time the invitations were sent via email), some of the unit managers had to decide on the day of the FGI itself. Unforeseen circumstances on the day of the FGI, such as absences in the unit and other assignments, were prioritized over participation in the study. In my opinion, the administration's engagement and enthusiasm in taking part in research studies and other developmental undertakings, could also influence the healthcare workers' own commitment to partaking in said efforts.

Using a small number of participants in an FGI (in this case, three (3)), has a positive and negative side. One of its strengths is that it promotes conversational unity (Cortini, et al., 2019, p.38). In this study, it seemed to help the participants feel more comfortable to express their views, and they also encouraged each other to engage in the discussion. They showed empathy towards one another (i.e., when one was narrating a negative experience, the rest listened and nodded). In addition, it became easier to collect the viewpoints of each participant, given the limited amount of time, and thus helped maintain a pleasant ambiance in the room. With a larger number of participants, a "blocking effect" could exist, where only a few get the time to speak, producing the tendency to dominate the discussion (Cortini, et al., 2019, p.30). This could ironically generate a lesser amount of ideas.

Recruitment in home care was a challenging part in Data Gathering. However challenging, I decided to conduct three FGIs to gather a substantial amount of information to be used in this study.

3.4.2 Translation process and analysis

I translated the data material from Norwegian to English independently. During the process, I took careful consideration not to alter the denotative meanings of each statement. I also received some feedback in the translation of some difficult words and expressions from my thesis adviser.

Being a speaker of Norwegian as a 3rd language, I decided to name relevant qualifications in this section. I hold a bachelor's degree in Teacher Education, major in Communication Arts – English, *cum laude* from the University of the Philippines from 2011. I also took an international English language test, the International English Language Testing System (IELTS) in 2015 and attained a band score of 8 out of 9, which corresponds to level C1 of the Common European Framework Reference (CEFR). English is also one of the two official languages of my home country. In 2016-2017, I earned level B2-C1 in Norwegian by taking the *Trinn 3 eksamen* (also equivalent to *Bergenstesten*) from the University of Oslo.

One of the reasons I chose not to use an external translator was, in my opinion, it would be better if someone with background in healthcare would do the translation, considering the context. This was hopefully covered by my bachelor's degree in Nursing Education (*Sykepleierutdanning*) from the University of South-eastern Norway in 2020. Another reason relates to the use of a third party, which was not declared in the application to perform research, submitted to the Norwegian Centre for Research Data (NSD).

Despite all these deliberations, some glitches could happen in the translation process, which could, in turn, affect the validity of data. This is one limitation in this study that must be considered.

Another occurrence that can be seen as a weakness to this study was the moderator's verbal remarks on some instances during the FGIs. I uttered words of affirmation to encourage the participants to continue their discussion when "dead air" occurred, or to console the interviewee who was airing out frustrations from the hardships she experienced during the covid-19 pandemic. At that moment, I thought that I was only doing the moderator's role of keeping the conversation flowing. However, it might have affected the respondents' feelings or attitudes towards the topic, and it might also be construed by others as somewhat «participating» in the interview. Although I did not experience it to be biased to the study, I cannot speak for the participants. This is, in any event, important to reflect on for possible future applications.

3.5 Ethical considerations

Informed consent forms were collected from the participants. Participation is voluntary and the participants were briefed about withdrawal from the study if they wished to. A copy of the Norwegian Centre for Research Data (NSD) approval and the information sheet with a sample consent form can be found in the Appendix section, p.72-74.

Informed consent form were sent to the respective establishment and unit managers, to be further disseminated to the target participants. Consent forms were collected via e-mail and physical meetup on the day of the FGI.

After the transcription, the audio files from the physical dictaphone loaned from the library were deleted, while the audio files saved online on the protected research tool, *Nettskjema*, created by the University of Oslo (UiO), were stored temporarily and were scheduled to be deleted when the study is completed. This is in correspondence with the Data Protection guide by the University of

South-eastern Norway (USN). Sensitive information accidentally divulged during the discussions were censored and eventually deleted. The study is anonymized.

4 Results

Thematic analysis of the data material led the author to three major findings, namely: 1) Homecare workers had varying views and understanding of the term 'psychosocial needs', as well as to whose responsibility its management was; 2) Homecare workers met ethical issues and dilemmas which affected the management of psychosocial needs during the pandemic, and 3) Person-centered psychosocial healthcare required interpersonal and organizational skills and competence. Only selected quotations are displayed on this chapter, and each participant was designated a number. A list of the quotations used in this section in both the original language and (Norwegian) and their English translation are provided in Annex 5, p.90.

4.1 ***Homecare workers had varying views and understanding of the term «psychosocial needs», and whose responsibility its management was.***

When the topic of meeting the psychosocial needs to attain psychosocial well-being was presented, most of the respondents took time to think about what it meant. When they were asked to enumerate possible ways to meet the psychosocial needs in relation to the users' well-being, some responded right away, while a few became silent for a moment before they could identify any.

For some, it meant meeting the relational needs like having people around and/or having someone to engage in conversations with. One mentioned having family members and keeping relationships. Another respondent added that it could also mean meeting the emotional needs, like the need to feel secured:

4: *«It is to have someone, like, beside [you], like, to experience security, and to have someone to talk to, those things.»*

Interestingly, one respondent described it as subjective, that is, it differed from person to person.

7: *«It's very personal, different from person to person. We have several who are almost dependent on getting a hug every day, and those who would barely see other people. They just limit themselves with those on TV. So you have at least a wide spectrum of needs, I think.»*

For many of respondents, participating in the activity center itself was the definition of having a sound psychosocial well-being. It was mentioned that home-dwelling elderly with dementia relied heavily on following routines, and thus, deviations in form of activity centers shutting down and/or being isolated due to COVID-19 infection resulted in negative emotional consequences. For instance, informants reported that many users found it difficult to understand the changes. Similarly, it was difficult for the workers to explain the changing guidelines to the usergroup.

1: «I think maybe, right away, that some of them with dementia have benefited from going to the activity center, for example. ... And it can have a negative impact on the psychosocial [well-being], in a way that one is not allowed to go out like they are used to, and maybe it was difficult to understand why it was like that, (and) that it was difficult to explain to them, maybe.»

The interviews also showed that the understanding of what psychosocial needs entailed might also had been affected by the COVID-19 pandemic. It had been pointed out that the pandemic made it almost impossible to manage these needs in place of the more urgent and basic health needs, like medication. Subjects expressed frustration over how resource-extensive the pandemic had been and how this led to deprioritization of psychosocial needs. One participant described the extent of following restrictions and guidelines as working with «bounded hands and feet». Psychosocial healthcare before and during the pandemic was compared as such:

3: «It was already, also, it's quite difficult from before. So when COVID came, so it was, in a way, put away on a shelf.»

This, according to an informant, was due to the fact that services like activity centers, physiotherapists, hairdressers and podiatrists who offered home service, and visitations from relatives and friends were reduced to control the spread of COVID-19 infection.

Whose responsibility was the managing of psychosocial needs?

Just like the previous question, the subjects gave differing answers. Some of them designated the responsibility to, as mentioned earlier, the activity centers, while for others, much of it had fallen on the shoulders of the relatives who actively volunteered to help during the pandemic.

1: *«It's the activity center, in a way, which has the main (responsibility), ... It has visiting [therapy] dogs as well. The place where you can get something of everything was in a way put on hold. And there's limitation to what home nursing care can do. We are there to talk, but it was limited how long we can sit there and talk.»*

A respondent suggested that the workers themselves had an important role in identifying users who needed help because they work hands-on with patients and thus, know the patients best.

6: *«Well, it's us. It's us who work in the health care system. We who know the patient best. When I come and visit a patient, I see a patient who has always been outside, and who always had been social. And all of a sudden, that patient couldn't go out alone. It's important to think, 'ok, will it benefit the patient to join the activity center?'. So, it's us, us who work in the health care sector, who have the responsibility for such things.»*

Another nurse informant pointed out that while psychosocial welfare management was a collective responsibility, the government and administration had control over the measures, and the power to do something and help the more vulnerable groups, like elderly with dementia.

5: *«It's on A.. the upper level, they can make exceptions for the weaker groups, for example. We felt that there wasn't much we could have done, when we were like locked in restrictions. We couldn't make our own rules. Rules were already made. Like, they should come from those who make the rules. The government. Like, the weaker groups should be taken care of. .. It's a collective responsibility, I'd say, there's no one who wants that responsibility, in a way. It's us at work, the administration, it's the.. We have to work together for it.»*

Meanwhile, a number of respondents directly replied that the question was difficult to answer and that they did not know. Possible implications of not having a common understanding of what psychosocial needs are and what impacts they might have on the users' over-all health, as well as lacking awareness of who or which are responsible for the management of these needs, will be discussed in the Discussion chapter.

4.2 Homecare workers met ethical dilemmas which affected the management of psychosocial needs during the pandemic.

The respondents in all three FGIs responded in unison that the pandemic presented ethical issues which affected how they managed the psychosocial needs of the usergroup. These issues ranged from conflicts between the healthcare worker and the patient, the relatives, and the community, as well as facing unhealthy working environments.

4.2.1 Deviating from rules and guidelines to meet users' need for social companionship and physical nearness

Healthcare workers reported having to deviate from the guidelines in order to meet the users' need for human contact and/or interaction. Personal assessment of the situation had to be done. Some of them even admitted to, for example, taking their masks off to make it easy for the users to identify them, and giving the user/s a hug during the latter phase of the pandemic.

7: «It's like what I said about (a user) who needed a hug to calm down. Or a hand to hold, to feel human contact. There were many who were not held through almost the whole pandemic, because they could manage on their own, so you didn't have to go to them. ... For those who could manage on their own and didn't have physical human contact in a very long time, you noticed somehow that there's a bit of desperation. Just to have a hug or to hold hands. In some cases, it was so bad that you just do it because it was what the patient needed at the moment. It was almost more important than the thought that maybe, I have the virus or that the patient has it.»

4.2.2 Difficulty in implementing infection control measures, providing treatment and carrying out testing procedures

Implementation of infection control measures was also challenging for the most part, when dealing with elderly with dementia due to the scope and severity of the disease, prolonged use of PPE, and encountering COVID-19 deniers.

Respondents expressed difficulty in performing COVID-19 protocols whenever there was a question of using force or restrain towards elderly patients with dementia who were, for the most part, suffering from symptoms of forgetfulness and confusion. This can have an effect in psychosocial

healthcare because prolonged isolation as an infection control measure normally equates to prolonged isolation from the users' normal routines and social meetings. Some of the patients refused to be tested, and informants faced the dilemma of performing procedures against physical and verbal reluctance and unwillingness:

7: «I've encountered several who were very much against testing. Specially with the deep nasal swab test. Where I had to use a long time in advance to explain, but then, they've forgotten all about it right after you opened the swab kit. Then they get terrified when they feel it going up inside the nose, even if you explain the whole time what was going to happen. They start banging their heads and say, 'stop, stop, no, i don't want to'. I couldn't continue. There was no decision on use of force there. I couldn't do it and take the test.»

In other cases, users ignored healthcare workers until facemasks were removed. Respondents mentioned that they were shouted at and instructed to remove their facemasks. Some respondents admitted to removing their facemasks while maintaining distance from the users, for example, keeping themselves in the kitchen while the user was in the living room.

One respondent also met patients who were supposed to be isolated, outside their homes. If the patient was living with a spouse, the spouse usually led the patient back inside the house. However, for patients living on their own, the respondents reported frustration and worry, since they could not sit there and look after the patient for hours. Oftentimes, when the patients were seen wandering outside, the respondents would get phonecalls from concerned neighbors who, in one way or another, knew about the patient's isolation due to COVID-19 infection.

PPE as barrier to communication and contributing factor to increased risk of making medical errors

A major issue that has affected the management of psychosocial needs was, according to the informants, the use of PPE. While it was useful in preventing infection, it became a barrier to communication, in establishing trust with the users, and in performing tasks – measures that can be crucial in managing psychosocial needs. Respondents reported that users felt terrified and insecure when they couldn't recognize the person behind the PPE. It was also challenging to reason why healthcare workers had PPE on when patients were asymptomatic.

5: «You lost the communication aspect because they often read the lips and they would use the entire expression. When it comes to, or with the senses, it was like, with the gaze and the lips and

all, like the harmony and body language. ... And so we were asked to compensate, and that's by shouting. But then, they only hear the loud sounds and not the words. Such that they become more insecure, many were afraid, to say the least.»

Furthermore, the use of PPE could have also increased the risk for making medical mistakes, like delivering the wrong medicine dosage and administering the medicines improperly. The respondents discussed how breathing through facemasks could produce moist and fog up protective visors with plastic shields and/or eyeglasses, making it difficult to see when tending to wounds or administering medicines, like insulin injections. One of them admitted to not taking any chances and removing her eye protection to avoid committing a medical mistake. One could think that this did not have any impact on psychosocial healthcare, but facing these challenges could eat up time, which could have been allotted to managing non-medically related tasks. Furthermore, putting PPE on and taking them off also ate up most of the visitation time allotment. Respondents admitted to using lesser time with the patients because of this.

Encountering COVID-19 deniers

Another ethical problem healthcare workers faced was encountering relatives who could be referred to as the so-called *COVID-19 deniers or skeptics*. Respondents reported that having to deal with deniers often led to frustration and feeling of exhaustion. Respondents expressed their dismay when relatives openly exclaimed that they did not believe in COVID-19, or that they were infected while visiting their vulnerable elderly relatives. One respondent called this act of treating the pandemic as a joke, selfish and «very special», as those relatives seemed to think only of themselves and not the elderly users.

Another respondent commented:

7: «I think that those situations were difficult, when we informed the relatives that the patient had to be in quarantine, and so they still came to visit anyway. They came anyway. Or if I was homevisiting a user who's not isolated, not infected, just following the normal restrictions. And the relatives say in the middle of the visit, 'yes, I have corona infection'. Then. Some were just irritated as a healthcare worker, like, 'why did you come here, to an elderly person, if you know you are infected, even if you don't have symptoms? And why are you exposing me to the virus?'.

Relatives can play an important role in fulfilling the patients' need for social relations and emotional support while battling an acute disease like COVID-19. Respondents narrated how patients lighted up when relatives came to visit, and that many users had scheduled dinners with their families one day per week. Acting careless during the pandemic on the part of the relatives by not following infection control measures, as described by some of the respondents, not just put the patient's overall health at risk, but also had a demotivating effect for the healthcare workers who were trying to do their job.

4.2.3 The issue of confidentiality

This ethical concern presented a conflict not just between the healthcare worker and the user's privacy, but also concerned the society as a whole, by crossing some of the major laws and guidelines surrounding healthcare and public healthcare, like the Public Health Act (*Folkehelseloven, 2012*), Patient and User Rights Act (*Pasient- og brukerrettighetsloven, 2001*) and the ICN Code of Ethics for Nurses (*Yrkesetiske retningslinjer for sykepleiere, 2021*).

Some users live in communal blocks, making it difficult for the healthcare workers to give them privacy. Respondents said that the neighbors saw them coming, watched them changed into PPE, and eventually asked them questions about COVID-19. There was a concern for confidentiality, leaving the healthcare workers confused and even uncertain as to how they could follow the guidelines and at the same time, uphold what was indicated by the law and the guidelines. One of them commented that infection control might have weighed more during the height of the pandemic.

3: *«We have some, like, care homes (omsorgsboliger), municipal homes (kommunale boliger), several live in a block and know each other, so they see that we come and visit a user in full equipment, and maybe we received questions we couldn't answer because of confidentiality, so we have no chance to write a signage on the door or other places.»*

Due to lack of uniformity in guidelines, the respondents said that they felt confused and insecure about what they were doing. It was also more difficult to just assess the situation using their own understanding due to this uncertainty.

4.2.4 Feeling torn between the sense of duty and obligation and their own personal safety

Lastly, respondents reported that they felt torn between the pressure of adhering to the sense of duty and responsibility and to their own personal safety. This internal conflict was more evident amongst the respondents working as assistants, with one of them sharing that there was a big need to work several double-shifts and that there was much overtime. Having the constant danger of getting infected made several of the respondents use little time with the patients, concentrating on bodily needs and putting the psychosocial ones for later. There was also the possibility of experiencing a burnout and increased absences, which could, in turn, have negative consequences on providing psychosocial healthcare.

6: «You know what, like, that inner feeling, when we were asked if we could work, yes, when they come in and say, 'yes, we have absences because of illness or infection, we have no one who can work', and I sat and thought, ok, if I say no and you say no and she says no, and he there says no as well, who's going to work then? And there's that patient sitting at home and really needing your help. I also have my own family at home, and you had to, like, put your family aside. For the patients really. So it was very tough, and many of us in home care had done that. To put your family aside.»

4.3 Person-centered psychosocial healthcare required interpersonal and organizational skills and competence.

The third theme refers to how the respondents managed the psychosocial needs of the usergroup in a person-centered manner. Respondents reported concrete measures that were implemented, and gave suggestions for future improvements along the way. Providing person-centered psychosocial healthcare was tough, according to the respondents. It required not just skills, but a combination of training and knowledge.

4.3.1 Knowledge about dementia was crucial

Despite the challenges and ethical and practical dilemmas encountered during the pandemic, healthcare workers used their knowledge, skills and creativity to meet the psychosocial needs of elderly users with dementia. They reported that having competence in this area became very beneficial, although not all home care units had resource persons specializing in dementia.

1: «I remember that I tried somehow to use a little more time for conversations and tried to make the ambiance lighter. I remember calling myself an Easter chicken, when I arrived in yellow costume, and did something funny. And tried to spend some time to be as clear as I could, to use a little extra time for the conversation with the first (second) I put (protective) clothes on me, in a way. To be there. But it is... It is important, for example, specially for dementia, to keep the routines at the exact same time. Because a deviation can lead to delirium. If there's a change or something, yes. I've experienced it happen, but it was change in the environment and routines that can be a trigger factor.»

Knowledge about the disease, its course and development, and the symptoms involved, became crucial in analyzing changed behavior and determining whether it stemmed from the pandemic or from the disease itself. Participants pointed out that knowing dementia and the user suffering from it helped them come up with creative, although not fully person-centered, solutions. For example, striving to have fast routines and sending the same personell, adjusting the measures to provide effective communication, and using relevant welfare technology and collaborating with the relatives.

4.3.2 Use of welfare technology

Several informants pointed out that the use welfare technology, especially phone consultations and medicine dispensers, helped them get through the pandemic.

8: «Phone consultations are actually a step further into ending visitations, it belongs to home care services. We go from visiting and doing tasks to phone calls, for we've started to reduce the visitations, and so everyone is finished in a way.»

However, many of them felt that there were not enough available options due to economic reasons. In addition, they reported that the available options were made for the general population, and less of it catered or was oriented towards elderly with dementia. They believed that several technological measures could have made things better, like using screens for video calls. A number of them were also aware of technology's impact on psychosocial well-being, commenting that using phone consultations and relying on medicine dispenser was anti-social and left the patients under-stimulated.

In addition, respondents had a little discussion on the side about the importance of having welfare technology that was personalized for elderly with dementia, had easy features or functions to use, and tested against stimuli that could heighten symptoms, like intense light and color. One group also discussed the «language» in welfare technology, (i.e., it should be a language that the user understand). They referred to the security alarm (*trygghetsalarm*) that was connected to a command center in the northern part of Norway, which spoke a challenging dialect. Respondents reported that users were confused when coming in touch with someone they couldn't understand, as most of the users in the south had never been to the north. Those users ended up disconnecting the call and searching for other means to find help.

4.3.3 Prioritizing and advanced and careful planning

Prioritizing, advanced and careful planning, and being solution-oriented also helped the workers to carry out their tasks. Some of them pointed out that it was important to include the users and the doctor, eventually, the relatives, in order to have an effective and successful planning. They made priority lists and planned their visitations in advance. However, there were times when their plans did not work and they had to come up with alternative solutions which would cater to specific users.

9: «Actually, we made plans, for example, limited visitations. So, the users agreed to that, as well as the GP/doctor, that it's not going to be a health hazard. ... So it wasn't just us deciding over which services or visitations or restrictions, like that. It's also conferred with the doctor and the users themselves.»

Furthermore, respondents reported that being better in assessing patient situations and practicing proper time management could be considered as the silver lining during the pandemic.

Collaboration with the relatives and other healthcare professionals

Respondents also detailed the role relatives played on psychosocial welfare management. Many relatives gave an impression of having a greater understanding and tolerance to change during the pandemic. They agreed to extend extra help and became more participative by doing the patient's grocery shopping or their laundry.

However, not all users had relatives to depend on, and there were relatives who handed over the full responsibility to home care workers due to fear of catching or bringing the virus with them. Some patients didn't have good relationships with their relatives, and so, they ended up more alone during the pandemic.

6: «It's and-or-or. It's different from relatives to relatives. Some were very good, and some tried to, okay, keep their distance from home care, and said, 'we're keeping our distance', right. It's like that. So.. But most of them are good and took care of things, I guess. So yes.»

Summary

Several informants reported that they did not have much capacity and capability to meet the psychosocial needs of the patientgroup during the pandemic. Many of them felt that the restrictions were too much, and that hindered person-centered care, however hard they tried to personalize the services, and apply careful planning and prioritizing. This became more actual because of the ethical dilemmas that came with the pandemic, as well as the varying views and understand of what psychosocial needs really mean and what role they play in its management.

Hence, the suggestions they gave for future improvements resonate with their experiences, for example, an emphasis on the significance of keeping the activity centers open, at least for elderly users with dementia. According to them, this usergroup are used to following routines. A break in routines could cause confusion, fear, loneliness, and worsening of their symptoms.

Some of the informants also highlighted the importance of welfare technology and the need to explore all the possibilities within it. In addition to medicine dispensers, respondents discussed the possibilities within training applications, communication screens, robot pets, GPS and video consultations. There was a consensus that welfare technology should be personalized and offered to users who actually wanted and needed them.

The respondents also reported the need to focus on preventive measures and contingency plans and crisis plan with common guidelines. To answer to the question of uncertainty and competence at work, they suggested that repetitive practice on the proper use of equipment and educating potential resource staff could be beneficial and economical for the public homecare system. Better staffing was another area they wanted focus on. Two of the respondents also mentioned that there was a need to consider users with substance abuse and dementia in the guidelines.

In light with the research findings, I chose to discuss 1) the implications of having varying and inadequate understanding of psychosocial needs, and the lack of awareness on who or which entity is responsible for its management, 2) why it is necessary to address the ethical issues that home care workers experienced during the pandemic, and 3) what learning nuggets we can get from these experiences which can promote person-centered psychosocial healthcare on top of priority lists.

5 Discussion

Through this study, it came to light that managing the psychosocial needs of COVID-19 isolated elderly with dementia still living at home in Norway had been tough for the most part during the pandemic. Home care workers reported not being able to fully meet the psychosocial needs of the user group due to restrictions and guidelines imposed to treat and to control the spread of the viral disease. In this section, I would like to discuss three important areas that were highlighted in the findings, namely: the need for a common understanding of "psychosocial needs" and of which entities are involved in its management, the need to address the ethical issues and dilemmas experienced by home care workers during the pandemic, and how the experiences of home care workers can be used as a learning arena for future improvements in psychosocial healthcare of home-dwelling elderly with dementia.

5.1 Psychosocial needs and its management: A need for a common understanding

As mentioned earlier, meeting the needs associated with psychosocial well-being and the ability to independently care for one's self is understood to be a collective or common responsibility for each healthcare worker, both those who work hands-on with patients and those with administrative roles. The municipal healthcare system has an obligation to lay out written procedures in catering to the individualized needs of all users, including users with dementia and users with difficulty in expressing their needs (Norwegian quality regulations for nursing care services, *Kvalitetsforskriften for pleie- og omsorgstjenestene*, 2003, §3). However, informants in this study expressed different opinions and views on managing the psychosocial needs of COVID-19 isolated elderly with dementia who are still living at home.

Some of them pinpointed that the activity centers had the main responsibility, even before the pandemic happened. They reported that they simply didn't have the time to provide psychosocial services, which most of them associated with sitting down and conversing with the users. And thus, the activity centers were supposedly tasked to cover those needs. Other informants, mostly working as nurses, indicated that meeting these needs had something to do with politics and administration. The provision of psychosocial services was restricted by infection control measures, implying that if the administration had made exceptions for vulnerable groups like elderly with dementia, it would have been more practical for home care workers to meet the psychosocial needs.

But what implications can having different understanding of what psychosocial needs are and who or which entity/ies should be working to fulfill them? How does it affect psychosocial healthcare when someone says «I don't know» when asked to name some psychosocial needs a patient might have and who is/are responsible for its management?

Psychosocial needs during an acute disease can be understood by looking at the disease as a “lived phenomenon”, meaning, how the patient experienced being sick, in this case, with COVID-19 (Stubberud, 2019, p. 16-17). Ehrenberg, et al. (1996) defined psychosocial needs as consisting of the emotional and the relational aspects. The relational aspect of psychosocial well-being, according to Ehrenberg, et al. (1996) could mean the need for social contact and emotional support and/or the need for good relationships and meaningful social interactions. Each visitation that was being done in home care presented an opportunity to fill up this particular need in a user. However, most of the respondents were focused on external measures (e.g. activity centers, social gatherings, etc.), that would satisfy these needs. It could have happened that home care workers overlooked the fact that their interaction with the users during visitation could be considered as a measure in itself to meet psychosocial needs, since it is part of the whole *experience of being sick*. Very few respondents expressed awareness of this, relaying that they used themselves to create a lighter ambiance during visitations and tried to establish good rapport and trust during their interactions with the users.

Differences in responses, views and understanding of what psychosocial need entails could mean varying levels of commitment and quality of services, and in some cases, failure to accommodate individualized or person-centered needs. In a study conducted by Hansen, et al. (2017), home care workers tend to use three different logic in meeting the psychosocial needs of home-dwelling elderly with dementia. I will now try to connect their findings with the responses from the informants in my study.

According to Hansen, et al. (2017), some home care workers use the *physical need-oriented* logic, where the focus was meeting the somatic or bodily needs as separated from the psychosocial. This logic became apparent for respondents in this study who delegated the responsibility of meeting the psychosocial needs to the activity centers alone, while the home care workers take care of the bodily needs. The next logic was the *renouncement*, where workers see the psychological needs as basic, but see the physical needs as more important. Some of my respondents reported that the psychosocial needs were acknowledged, but that they were not prioritized or even “put away in a shelf” during the COVID-19 pandemic. Many of them referred to bodily needs (particularly the acute

ones) on top of their priority lists. If the task was not acute, for example, going on walks with the user, then, they put it away for later.

The third and final logic was the *integrated* one, where both the psychosocial and the bodily needs were seen as essential. Only a number of my respondents indicated consciousness or awareness that their main presence during visitations was an integral part of meeting the psychosocial needs of the users. One of them expressed frustration when she had to work double-shifts, knowing that a patient was sitting alone at home, waiting for her visit. The respondent considered psychosocial as equally important as bodily needs, and thus, went out of her way to go and visit the person. Another respondent narrated that if the patient sent her a text message or called her, saying that «the TV does not work», she would normally drive back to the patient to turn it on for him/her. The respondent also said that she would do it even outside working hours, because she knew that the patient only relied on TV for pleasure.

Sharing a common understanding of what psychosocial needs are, or what it can be for a specific patient, and committing one's self to being a part of a whole system responsible to its management, can help in achieving the overall goals of home care, namely, helping the user cope with every day life in his/her own home, contributing to the life quality of users, and making sure that users could live at home for as long as fit and they desire (Fjørtoft, 2016, p.122). However, in order to accomplish this, all healthcare workers, not only in home care, need to have an awareness of this responsibility.

Furthermore, it is important to note that the subjectivity of psychosocial needs require the services to be individualized or person-centered (Kitwood, 1997). Most of the respondents expressed awareness that some users thrive in social gatherings, while others prefer to spend time alone with the TV or the radio. This is the point where the significance of *knowing the patient* comes in, although, according to Kitwood (1997), everyone has basic psychosocial needs which could lay the foundation for psychosocial health management for users with dementia. Everyone needs identity, love, comfort, occupation, inclusion and attachment. The healthcare worker only needs to find out how the patient prefers these needs to be fulfilled. And, of course, have the time and resources to actually manage. Lack of important resources, such as time and staff, could have hindered the healthcare worker from knowing how each user experienced being sick with the coronavirus, and paying extra attention to how the patients would want their emotional and relational needs met during that moment.

5.2 Addressing the ethical issues and dilemmas

Another important area to discuss is the need to address the ethical issues and dilemmas home care workers experienced during the pandemic. A number of ethical issues were reported during the interviews, including conflicts involving the healthcare worker and the nursing profession, the users, the relatives and the community as a whole. What impacts did these dilemmas have on managing the psychosocial needs of the patients? Why is it important that home care workers be given the venue to reflect on these experiences, and were they given the chance to after the pandemic was over?

In this section, I looked at the revised Nursing Code of Ethics published by the International Council of Nurses (ICN) in 2021, and tried to connect its relevance to the findings of this study. While the new Code maintains the ethical guidelines in terms of the nurses' relationship with the patients and other people in need of healthcare, with the nursing practice and profession, it also stresses that nurses have a duty to promote health globally. Furthermore, the guidelines highlights the role of nurses in preparing for and responding to emergencies, disasters, conflicts, epidemics, pandemics, social crises and conditions of scarce resources (ICN, 2021, p.15).

The Nursing Code of Ethics (ICN, 2021, p.12) specifies that “nurses value their own dignity, well-being and health» by requiring «positive practice environments, characterised by professional recognition, education, reflection, support structures, adequate resourcing, sound management practices and occupational health and safety». Home care workers reported to have experienced pressure in carrying out their jobs in compromised working environments. They were conflicted or torn between the sense of duty and obligation as a healthcare worker and their personal safety. In the end, most of them chose to provide clinical care to the users while hoping that they did not catch the coronavirus and possibly spread it back home to their families. A nursing assistant also found it difficult to avoid working double shifts and overtime when there was a dire need for staffing. These experiences were contradictory to what the Code suggests.

Other ethical concerns revolved around the patients, such as creating deviations from infection control guidelines in order to satisfy the users' psychosocial needs, conducting testing procedures despite users' unwillingness to cooperate, and removing PPE to avoid committing medical errors during treatment and other clinical procedures. These ethical dilemmas added up to the uncertainty that the home care workers were already feeling due to the COVID-19 being a “new disease”. The Code of Ethics (ICN, 2021, p.12) dictates that “nurses carry personal responsibility and

accountability for ethical nursing practice” and uses their «professional judgement when accepting and delegating responsibility”, such that they maintain practice within the scope of their own individual competence. As evidenced by the responses from the interviews, in addition to possessing competence and skills in dementia and home care, there was also a need to consider the external factors, like the working environment, use of equipment, and the users’ living and health situations. A stressful working environment where workers are constantly met with ethical dilemmas, can contribute to the difficulty of meeting the psychosocial needs of the patients.

Nurses, at all times, shall also “maintain standards of personal conduct ... which reflect well on the profession and enhance its image and public confidence” (ICN, 2021, p.12), and “hold in confidence personal information and respect the privacy, confidentiality and interests of patients in the lawful collection, use, access, transmission, storage and disclosure of personal information» (ICN, 2021, p.7). Respondents in this study narrated how difficult it was for them when encountering relatives who were COVID-19 deniers and answering personal questions from other people living in the same settlements as their patients. One respondent reported that it was challenging to maintain composure and act professionally when relatives came to visit their sick family members and announced that they were COVID-19 infected.

Needless to say, home care workers should not feel alone in handling these ethical issues and should be provided with venues for reflection and discussion with co-workers or their leaders. Many of them relayed that they did not have the chance to sit down and talk about the pandemic after the restrictions were lifted. Respondents also reported that in addition to the already burdensome ethical problems, there were many changes in work organizations in response to the pandemic crisis. They had to adapt simultaneously to these changes. It was also challenging for them to act and manage, not just the psychosocial needs but the over-all health of the patient, when they faced several decisions that were contradictory to the Code of Ethics and healthcare-related laws and guidelines.

Another way to address these ethical issues can be to empower home care workers in their roles as healthcare providers, encouraging them to participate actively “in creating a positive and constructive practice environment where practice encompasses clinical care, education, research, management and leadership” and to «contribute to positive and ethical organisational environments and challenge unethical practices and settings» (ICN, 2021, p.15). After each of the interviews, the respondents expressed satisfaction in being able to discuss and reflect on their experiences during the pandemic. Although most of them expressed concern over the needs of the users, and often

considered those needs above their own, everyone agreed that it was important to discuss how the healthcare worker lived through the challenges during the pandemic. Participants commented that the FGIs helped them process the situation and could potentially contribute to developing future measures which can help ensure that the psychosocial needs of this vulnerable patient group are met. Furthermore, the interviews also served as a tool for them to be more aware of their own psychosocial needs.

5.3 Home care workers' experiences of the COVID-19 pandemic and future improvements in person-centered psychosocial healthcare

It is every nurse's personal responsibility to maintain competence by engaging in continuous professional development and lifelong learning, according to the Nursing Code of Ethics (2021, p. 12). The pandemic brought about many challenges in the home care system, but it also came with some silver linings. Many respondents saw the pandemic as an opportunity to work more tightly with their colleagues and other healthcare professionals. A handful of them expressed their increased appreciation for the relatives who were participative all throughout the COVID-19 pandemic. And still, many of the respondents considered the entire situation as a learning arena and reported how their observation and careful planning skills were improved.

However, psychosocial welfare management still needs to be prioritized and focused on, with or without a pandemic crisis, specially among elderly users with dementia. Many members of this vulnerable user group have reduced physiological and cognitive capacity (Wyller, 2020, p. 277), and thus, difficulty in expressing their psychosocial needs. One can even argue that since the cognitive health, in addition to physiological health, was affected and/or weakened, patients with dementia are more emotionally and socially vulnerable than user groups suffering from just somatic diseases. This is supported by earlier research findings (Taylor, et al., 2021; Kales, et al., 2015). If that is the case, then, the need for psychosocial welfare management among this particular usergroup, helping them maintain pleasant living environment and have emotional stability, should be more emphasized and accommodated, especially during a coronavirus pandemic when contraction of the virus and implementation of infection control measures could heighten the neuropsychiatric symptoms of dementia (Wei, et al., 2022; Suarez-Gonzales, et al., 2020).

Moreover, there is the pressing need for the capability to provide evidence informed and person-centred care. Implementation of person-centered psychosocial healthcare necessitates modifying

care to cater to individual preferences (Nasjonalt senter for aldring og helse, n.d.), and thus, requires knowledge of the patient. Respondents agreed that it was important to strive for continuity by sending the same workers to a certain user with dementia. It was not just because it would be easier for the said user to remember and recognize the worker, but also for the worker to «know» the user, relate with the user, and enhance the ability to observe changes in the user's health condition. In that way, person-centred services can be offered, and eventually delivered, to all users. Although the question of how to provide psychosocial healthcare that is person-centered during a pandemic, when major changes and modifications are already being made in many aspects of healthcare, remains. That is, how person-centeredness, psychosocial healthcare, and urgent health crisis response all cook in one pot.

The Royal Norwegian Ministry of Health and Care Services (*Helse- og omsorgsdepartementet, HOD*) has published the Dementia Plan 2025 (*Demensplanen 2025*), a comprehensive five-year plan aiming to improve the services offered to persons with dementia and their relatives. It aspires to ensure a longterm and holistic planning of local communities and other units, as well as dimensioning and improving the quality of services, through dialogues with users and their relatives and other relevant organizations (HOD, 2020). Among the objectives of the plan are to ensure co-determination and active participation in a dementia-friendly environment, taking person-centered and individualized dementia care into consideration, and to widen research and knowledge of the treatment and prevention of the disease. However, implementation of these measures during a pandemic, in the case of COVID-19, lasting years, needed attention and planning. In the document, it was named that some services were put on hold or reduced due to the coronavirus pandemic, some of which were important recreational- and activity services for both users and their relatives, for example, activity centers, home care services (HOD, 2020, p. 26), which could have had a negative impact on psychosocial health.

Nonetheless, the plan acknowledged the potential role of welfare technology in controlling the spread of infection during the pandemic (HOD, 2020, p.45), the principle of building small, easy-to-oversee settlements and rehabilitation services in the future (HOD, 2020, p.71), and the engagement of non-profit and volunteer organizations (HOD, 2020, p.47), with the government offering financial support to encourage these groups to come up with good recreational services for patients with dementia.

The respondents also came up with suggestions on how their experiences can be used in future public health crisis situations. More research on welfare technology, preventive and contingency plans, courses on infection control measures, and building a social network for each user are among the proposed action plans in the future. In relation to use of welfare technology, nurses need to “ensure that the use of technology and scientific advances are compatible with the safety, dignity and rights of people” (ICN, 2021, p.8), including the use of artificial intelligence (AI), for example, pet robots, such that the care still remains person-centered. Respondents seemed aware of this, quoting that although technology can help in many ways, it can also leave the patient under-stimulated and feeling more isolated.

6 Conclusion

This study looked on the experiences of home care workers in managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia during the coronavirus pandemic in Norway. Although respondents reported that psychosocial well-being was of utmost importance for the patientgroup, there appears to be a need for a clear, concise and common understanding of what it entailed and to whose responsibility its management was. Lack of understanding and ownership to the responsibility, in addition to strict recommendation to follow rules and restrictions, could have had an impact on the provision of an adequate and person-centered psychosocial care.

Ethical dilemmas experienced by home care workers should also be addressed. Among the ethical dilemmas discussed were committing deviations from guidelines and routines to meet users' needs for social companionship; having difficulty in implementing infection control measures, providing treatment and carrying out testing procedures due to the scope and severity of the dementia syndrome, prolonged use of PPE, and encountering COVID-19 deniers; meeting challenges to uphold confidentiality in communal settlements; and feeling pressured to carry out their job, while keeping themselves safe and healthy at the same time. A venue for discussion and reflection could help them process the whole situation and make room for analyzing which measures worked, did not work, and/or needed improvement. Furthermore, there is a need to empower home care workers on their role as healthcare providers.

Nevertheless, in spite of the challenges and hardships to meet the psychosocial needs of elderly with dementia during the coronavirus pandemic, home care workers saw the entire situation as a learning arena. The importance of knowledge, having adequate resources, advanced and careful planning, and collaboration with others, was emphasized.

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Note:

This document uses the APA 7th formatting style. The Latin abbreviation, "ibid.", is not used in this style.

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Appendix

A. NSD approval

Autumn 2022

11.07.2022, 11:44 Meldeskjema for behandling av personopplysninger

[Meldeskjema](#) / [Helsepersonells erfaringer ved ivaretagelse av psykososiale behov hos ...](#) / Vurdering

Vurdering

Dato	Type
06.07.2022	Standard

Referansenummer
373303


Prosjektittel
Helsepersonells erfaringer ved ivaretagelse av psykososiale behov hos covid-19 isolerte hjemmeboende eldre med demens
(Psychosocial welfare management of COVID-19 isolated home-dwelling elderly with dementia during the coronavirus pandemic)

Behandlingsansvarlig institusjon
Universitetet i Sørøst-Norge / Fakultet for helse- og sosialvitenskap / Institutt for sykepleie- og helsevitenskap

Prosjektansvarlig
GRETE BREIEVNE

Student
MAEROSE S CLAUSEN NIELSEN

Prosjektperiode
01.08.2022 - 15.01.2023

[Meldeskjema](#) 

Kommentar
OM VURDERINGEN

Personverntjenester har en avtale med institusjonen du forsker eller studerer ved. Denne avtalen innebærer at vi skal gi deg råd slik at behandlingen av personopplysninger i prosjektet ditt er lovlig etter personvernregelverket.

Personverntjenester har nå vurdert den planlagte behandlingen av personopplysninger. Vår vurdering er at behandlingen er lovlig, hvis den gjennomføres slik den er beskrevet i meldeskjemaet med dialog og vedlegg.

VIKTIG INFORMASJON TIL DEG

Du må lagre, sende og sikre dataene i tråd med retningslinjene til din institusjon. Dette betyr at du må bruke leverandører for spørreskjema, skylagring, videosamtale o.l. som institusjonen din har avtale med. Vi gir generelle råd rundt dette, men det er institusjonens egne retningslinjer for informasjonssikkerhet som gjelder.

TYPE OPPLYSNINGER OG VARIGHET

Prosjektet vil behandle alminnelige kategorier av personopplysninger frem til 15.01.2023.

LOVLIG GRUNNLAG

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 og 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a.

PERSONVERNPRINSIPPER

Personverntjenester vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke behandles til nye, uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), og dataportabilitet (art. 20).

Personverntjenester vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER

Personverntjenester legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

Ved bruk av databehandler (spørreskjemaleverandør, skylagring eller videosamtale) må behandlingen oppfylle kravene til bruk av databehandler, jf. art 28 og 29.

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og/eller rådføre dere med behandlingsansvarlig institusjon.

MELD VESENTLIGE ENDRINGER

Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til oss ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde: <https://www.nsd.no/personverntjenester/fylle-ut-meldeskjema-for-personopplysninger/melde-endringer-i-meldeskjema>. Du må vente på svar fra oss før endringen gjennomføres.

OPPFØLGING AV PROSJEKTET

Personverntjenester vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

TAUSHETSPLIKT

Deltagere i prosjektet har taushetsplikt. Intervjuene må gjennomføres uten at det fremkommer opplysninger som kan identifisere brukere

Kontaktperson ved Personverntjenester: Silje Fjelberg Opsvik
Lykke til med prosjektet!



[Meldeskjema](#) / [Helsepersonells erfaringer ved ivaretagelse av psykososiale behov hos...](#) / Vurdering

Vurdering av behandling av personopplysninger

Referansenummer
373303

Vurderingstype
Automatisk

Dato
20.01.2023

Prosjekttittel

Helsepersonells erfaringer ved ivaretagelse av psykososiale behov hos covid-19 isolerte hjemmeboende eldre med demens (Managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia during the coronavirus pandemic)

Behandlingsansvarlig institusjon

Universitetet i Sørøst-Norge / Fakultet for helse- og sosialvitenskap / Institutt for sykepleie- og helsevitenskap

Prosjektansvarlig

GRETE BREIEVNE

Student

MAEROSE S CLAUSEN NIELSEN

Prosjektperiode

01.08.2022 - 15.05.2023

Kategorier personopplysninger

Alminnelige

Lovlig grunnlag

Samtykke (Personvernforordningen art. 6 nr. 1 bokstav a)

Behandlingen av personopplysningene er lovlig så fremt den gjennomføres som oppgitt i meldeskjemaet. Det lovlige grunnlaget gjelder til 15.05.2023.

[Meldeskjema](#)

Grunnlag for automatisk vurdering

Meldeskjemaet har fått en automatisk vurdering. Det vil si at vurderingen er foretatt maskinelt, basert på informasjonen som er fylt inn i meldeskjemaet. Kun behandling av personopplysninger med lav personvernulempe og risiko får automatisk vurdering. Sentrale kriterier er:

- De registrerte er over 15 år
- Behandlingen omfatter ikke særlige kategorier personopplysninger;
 - Rasemessig eller etnisk opprinnelse
 - Politisk, religiøs eller filosofisk overbevisning
 - Fagforeningsmedlemskap
 - Genetiske data
 - Biometriske data for å entydig identifisere et individ
 - Helseopplysninger
 - Seksuelle forhold eller seksuell orientering
- Behandlingen omfatter ikke opplysninger om straffedommer og lovovertridelser
- Personopplysningene skal ikke behandles utenfor EU/EØS-området, og ingen som befinner seg utenfor EU/EØS skal ha tilgang til personopplysningene
- De registrerte mottar informasjon på forhånd om behandlingen av personopplysningene.

Informasjon til de registrerte (utvalgene) om behandlingen må inneholde

- Den behandlingsansvarliges identitet og kontaktopplysninger
- Kontaktopplysninger til personvernombudet (hvis relevant)
- Formålet med behandlingen av personopplysningene
- Det vitenskapelige formålet (formålet med studien)
- Det lovlige grunnlaget for behandlingen av personopplysningene
- Hvilke personopplysninger som vil bli behandlet, og hvordan de samles inn, eller hvor de hentes fra
- Hvem som vil få tilgang til personopplysningene (kategorier mottakere)

- Hvor lenge personopplysningene vil bli behandlet
- Retten til å trekke samtykket tilbake og øvrige rettigheter

Vi anbefaler å bruke vår [mal til informasjonsskriv](#).

Informasjonssikkerhet

Du må behandle personopplysningene i tråd med retningslinjene for informasjonssikkerhet og lagringsguider ved behandlingsansvarlig institusjon. Institusjonen er ansvarlig for at vilkårene for personvernforordningen artikkel 5.1. d) riktighet, 5. 1. f) integritet og konfidensialitet, og 32 sikkerhet er oppfylt.

B. Participant information sheet and Consent form

Vil du delta i forskningsprosjektet

” Helsepersonells erfaringer ved ivaretagelse av psykososiale behov hos COVID-19 isolerte hjemmeboende eldre med demens koronapandemien (Psychosocial welfare management of COVID-19 isolated home-dwelling elderly with dementia during the coronavirus pandemic) ”?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å undersøke hvordan helsepersonell ivaretok psykososiale behov hos isolerte hjemmeboende eldre med demens under koronapandemien. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Hensikten med studien er å belyse de psykososiale behovene av COVID-19 isolerte hjemmeboende eldre med demens og hvordan de ble ivare tatt av hjemmesykepleietjenesteutøvere. Studien vil rette søkelyset mot personsentrert omsorg og finne ut hvilke tiltak og tilpasninger som ble iverksatt. Det vil også finne ut hvordan helsepersonell samarbeidet med pårørende / sosiale nettverk. Studien har som mål å bidra til kvalitetsforbedring av hjemmesykepleietjenester og demensomsorgen, spesielt hos hjemmeboende eldre med demens.

Studien er en masteroppgave ved Master i klinisk helsearbeid – retning geriatrisk helsearbeid, Institutt for sykepleie og helsevitenskap ved Universitetet i Sørøst Norge.

Hvem er ansvarlig for forskningsprosjektet?

Universitetet i Sørøst Norge er ansvarlig for prosjektet.

Hvorfor får du spørsmål om å delta?

Du blir bedt om å delta fordi du jobber i kommunehelsetjenesten og har hatt erfaringer med behandling av covid-19 infeksjon hos hjemmeboende eldre med demens. Din kunnskap kan bidra til kvalitetsforbedring og organisering av helsetjenester for hjemmeboende eldre med demens.

Ingen personlige opplysninger om pasienter eller brukere skal inkluderes i prosjektet, kun dine erfaringer og opplevelser ved ivaretagelse av psykososiale behov hos hjemmeboende eldre med demens som var smittet av COVID-19 viruset og måtte isoleres.

Hva innebærer det for deg å delta?

Masterstudien har et utforskende og beskrivende design. Fokusgruppeintervju (FGI) skal anvendes som metode. Det vil være 6-8 deltakere i gruppen og intervjuet vil ta 1-1,5 time. Det skal være en moderator og en sekretær til stede som tar lydopptak og notater fra intervjuet. Hvis du velger å delta i prosjektet, innebærer det at du møter opp til avtalt tid og sted sammen med de andre deltakere.

Det er frivillig å delta

Det er frivillig å delta i studien. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Jeg vil også be om informasjon om deg, som yrke og stillingsstatus, under datainnsamling. Personlige opplysninger skal aidentifiseres i selve oppgaven. Det betyr at personlige opplysninger skal omarbeides ved bruk av en kodeliste, slik at du ikke skal gjenkjennes i selve oppgaven.

Hva skjer med personopplysningene dine når forskningsprosjektet avsluttes?

Prosjektet vil etter planen avsluttes vår 2023, 15. januar. Etter prosjektslutt vil datamaterialet med dine personopplysninger anonymiseres/slettes. Det innebærer at direkte identifiserende opplysninger, som navneliste, slettes. Personopplysninger som signatur i samtykkeskjema og yrke og lydopptak skal behandles og lagres på en sikker måte, ved bruk av digitale verktøy som er anbefalt av USN.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Universitetet i Sørøst Norge har Personverntjenester vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke opplysninger vi behandler om deg, og å få utlevert en kopi av opplysningene
- å få rettet opplysninger om deg som er feil eller misvisende
- å få slettet personopplysninger om deg
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger

Hvis du har spørsmål til studien, eller ønsker å vite mer om eller benytte deg av dine rettigheter, ta kontakt med:

- Fakultet for helse- og sosialvitenskap, Institutt for sykepleie- og helsevitenskap, Universitetet i Sørøst Norge ved [redacted] eller Student [redacted]
- Vårt personvernombud: [redacted]

Hvis du har spørsmål knyttet til Personverntjenester sin vurdering av prosjektet, kan du ta kontakt med:

- Personverntjenester på epost (personverntjenester@sikt.no) eller på telefon: [REDACTED].

Med vennlig hilsen

Grete Breievne
(Forsker/veileder)

Maerose S Clausen Nielsen
(Student)

-

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet «*Hvordan ivaretok helsepersonell psykososiale behov hos COVID-19 isolerte hjemmeboende eldre med demens under koronapandemien?*», og har fått anledning til å stille spørsmål. Jeg samtykker til:

- å delta i Fokusgruppeintervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

(Signert av prosjektdeltaker, dato)

C. Interview guide

I. Innledning

(Presentasjon - moderator, sekretær*, deltakere)

II. Hensikt til prosjektet

Hensikten med masterstudien er å undersøke hvilke erfaringer dere hadde ved ivaretagelse av psykososiale behov hos COVID-19 isolerte hjemmeboende eldre med demens under koronapandemien. Det vil rette søkelyset mot personsentrert omsorg og finne ut hvilke tiltak og tilpasninger som ble gjort for å kunne sørge for psykososialt velvære hos smittede eldre med demens.

III. Spørsmål til Fokusgruppeintervju (FGI)

1. Hvordan har koronapandemien påvirket ivaretagelse av de psykososiale behovene? Beskriv med eksempler.
 - a. Hvilke psykososiale behov har hjemmeboende eldre med demens?
2. Hva gjorde du konkret for å ivareta psykososiale behov hos COVID-19 isolerte hjemmeboende eldre med demens? Beskriv med eksempler.
 - a. Hvilke områder måtte tilpasse eller justere for å ivareta psykososiale behov hos enkelte eldre med demens under isolasjon?
 - b. Hvem har ansvar for ivaretagelse av psykososiale behov?
 - c. Opplevde dere noen etiske dilemmaer i tilknytning til det å ivareta psykososiale behov?
3. Hvordan samarbeidet dere med pårørende eller sosiale nettverket til brukerne?
4. Hvordan kan erfaringene deres eventuelt anvendes i forbedring av psykososial omsorg hos hjemmeboende pasienter med demens?

IV. Oppsummering og avslutning

D. Clarification on the terms “well-being” and “welfare”

In healthcare, both terms are normally used interchangeably, with welfare referring to «the well-being of individuals, families and the community» (Australian Institute of Health and Welfare, 2021). In the context of this study, the terms can encompass both the subjective experience and the more objective aspects, like the actual living circumstances (Carlquist, 2015, p.80). Both psychosocial welfare and psychosocial well-being require the fulfilment of psychosocial needs, which encompasses both relational and emotional needs (Ehrenberg, et al., 1996).

I originally intended to use the term «Psychosocial welfare management» in the thesis title. However, to avoid confusion, the phrase «Management of psychosocial needs» was used instead.

E. Tables, figures and other graphics

Figure 1: Gjøra, L., Strand, B., Bergh, S., Borza, T., Brækhus, A., Engedal, K., Johannessen, A., Kvello-Alme, M., Krokstad, S., Livingston, G., Matthews, F., Mystad, C., Skjelleggrind, H., Thingstad, P., Aakhus, E., Aam, S. & Selbæk, G. (2021). Current and Future Prevalence Estimates of Mild Cognitive Impairment, Dementia, and Its Subtypes in a Population-based Sample of People 70 Years and Older in Norway: The HUNT Study. *J Alzheimers Dis* 79(3), 1213-1226. <https://doi.org/10.3233/JAD-201275>

Projections of people with dementia in 2020, 2050, and 2100 in Norway

	Year 2020	Year 2050	Year 2100	Ratio 2050/2020	Ratio 2100/2020
Total					
30–64	2,108	2,203	2,095	1.0	1.0
65–69	2,008	2,383	2,489	1.2	1.2
70–74	14,493	17,153	18,277	1.2	1.3
75–79	16,691	29,774	29,512	1.8	1.8
80–84	20,380	49,866	55,267	2.4	2.7
85–89	23,675	64,498	97,093	2.7	4.1
90+	21,762	70,912	175,402	3.3	8.1
Overall	101,118	236,789	380,134	2.3	3.8
Men					
30–64	1,057	1,106	1,055	1.0	1.0
65–69	783	936	999	1.2	1.3
70–74	8,140	9,748	10,568	1.2	1.3
75–79	8,349	15,544	15,788	1.9	1.9
80–84	8,814	24,202	27,870	2.7	3.2
85–89	8,370	28,290	45,520	3.4	5.4
90+	5,567	25,406	70,805	4.6	12.7
Overall	41,080	105,233	172,605	2.6	4.2
Women					
30–64	1,051	1,096	1,040	1.0	1.0
65–69	1,225	1,447	1,490	1.2	1.2

Projections based on population estimates by gender from Statistics Norway (main alternative).

Figure 2: Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S., Dias, A., Fox, N., Gitlin, L., Howard, R., Kales, H., Kivimäki, M., Larson, E., Ogunniyi, A., ... & Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet Commissions* 396(10248), 413-446. [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)

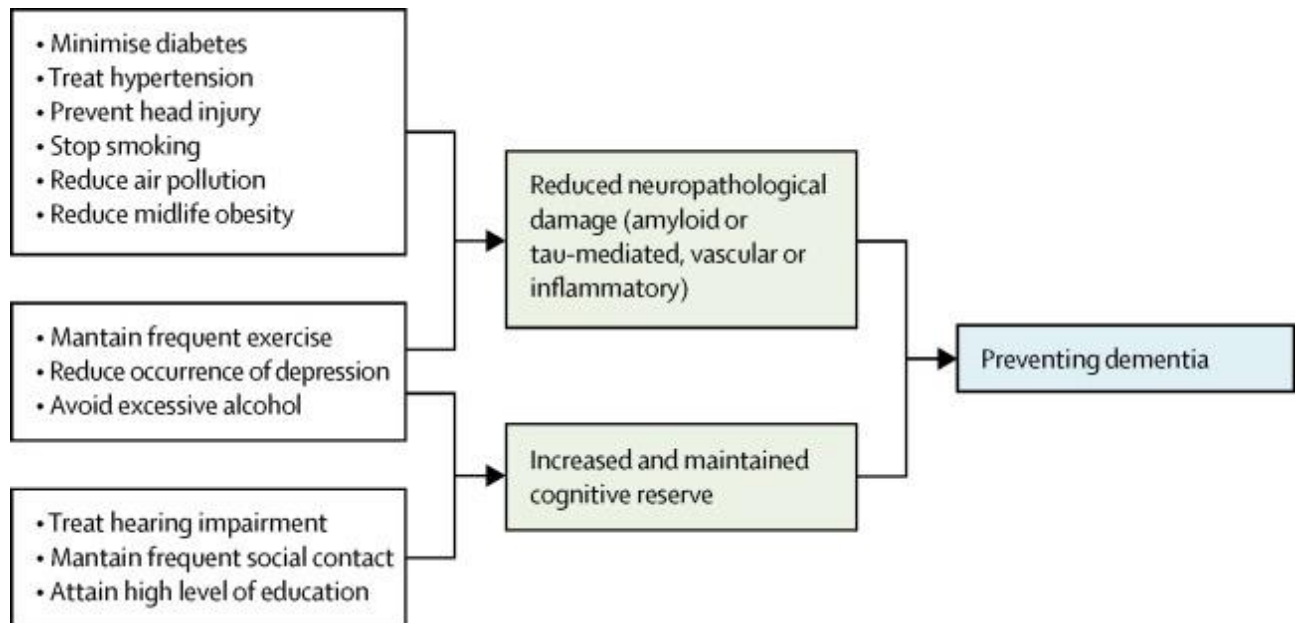


Figure 3: Inclusion criteria

- Registered / authorized personnel working in municipal home care system (nurses, nursing assistants, health workers, social workers, etc.)
- Has/had experience treating or working with COVID-19 isolated home-dwelling elderly people with dementia
- Has *fast turnus* or permanent working schedule (minimum 50% position), for continuity
- Can speak Norwegian or English language

Table 1: Participant demographics

Participant , age	Occupation	% position (<i>pr. stilling</i>)
F, 40s	Reg. Nurse	100%
F, 30s	Reg. Nurse	100%
F, 20s	Reg. Nurse	100%
F, 20s	Reg. Nurse	100%
F, ?	Reg. Nurse	100%
F, 50s	Nursing assistant	100%
F, 50s	Nursing assistant	75%
F, ?	Healthcare worker	100%
F, ?	Care assistant	70%

Table 2: Focus group interviews conducted

	No. of participants	Home care unit
FGI 1	2	a
Municipality A	1	b
FGI 2	2	c
Municipality A	1	d
FGI 3	1	e
Municipality B	1	f
	1	g
Total	9 participants	7 units

Raw data: Striking points from the interviews

- Among the challenges encountered by home care nurses in managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia are: the difficulty in explaining or informing the users and their relatives about infection control measures and the seriousness it entailed, managing the users' skepticism and resistance due to changing routines and protocols, communicative and medical barriers brought about by the use of personal protective equipment (PPE), and maintaining confidentiality.
- Respondents felt pressured in the workplace. It was difficult for many of them to prioritize, considering their own personal relationships and their own health.
- They described and narrated in detail their observations and experiences on how the users might have felt, including reactions like confusion, fear and panic, uncertainty, feeling isolated and lonely, embarrassment, shame (in some cultures), anxiety, feeling sicker, agitation and frustration, disturbed sleeping patterns, understimulation, refusal/resistance/skepticism, and the YOLO (You only live once) effect, where users intentionally ignored protocols and restrictions because of old age.
- Psychosocial needs seemed to have been forgotten and not prioritized during the pandemic. There were also varied answers as to who or which entity was responsible for it. There was an emphasis on the functionality of activity centers (*dagsentre*), and how shutting them down affected the users negatively. Phone consultations were highly used during the pandemic.
- Relatives were a big resource during the pandemic. They were described as solution-oriented, more participative and more understanding. However, they also met COVID-19 deniers. Some interviewees also expressed their dismay when no relatives were present, such that they had to take that role in the end.

Table 3: An overview of the chosen themes / subthemes

<h2 style="text-align: center;">Managing the psychosocial needs of COVID-19 isolated home-dwelling elderly with dementia during the coronavirus pandemic</h2>		
<p>Home care workers had varying views and understanding of the term “psychosocial needs”, and whose responsibility its management was.</p> <ul style="list-style-type: none"> •From meeting relational needs, like having someone to talk to, to fulfilling emotional needs, like feeling secured, or that it is something personal •The responsibility falls under one of the following: Activity centers, Relatives, A collective responsibility, Administration and government, or that the respondents didn’t know 	<p>Healthcare workers met ethical dilemmas which affected the management of psychosocial needs during the pandemic.</p> <ul style="list-style-type: none"> •Committing deviations from guidelines and routines to meet users’ need for social companionship and physical nearness •Difficulty in implementing infection control measures, providing treatment and carrying out testing procedures due to scope and severity of the disease, prolonged use of PPE, and encountering COVID-19 deniers •The issue of confidentiality / lack of privacy in communal settlements •Felt pressured: Torn between the sense of duty and obligation and their own personal safety 	<p>Person-centered psychosocial healthcare required interpersonal and organizational skills and competence.</p> <ul style="list-style-type: none"> •Knowledge of dementia was crucial in analyzing changed behavior and coming up with creative solutions •Use of welfare technology and phone consultations •Prioritizing and advanced and careful planning, including collaboration with relatives and other healthcare professionals

Annexes

Annex 1: Powerpoint presentation for the FGIs



Slide 1

- "Hvordan ivaretok helsepersonell psykososiale behov hos COVID-19 isolerte hjemmeboende eldre med demens under koronapandemien?"

- Introduksjon
- Hensikt
- FGI
- Avslutning/Oppsummering
- Q&A/Andre kommentarer/tilbakemeldinger

Slide 2

- FGI

- Det egner seg til å finne forbedringsområder og å kvalitetsvurdere tjenestene. (Helsebiblioteket, 2019)
- Uformell, men strukturert.
- Unngå å nevne sensitive/kjennbare informasjon om pasienten, som navn, adresse.
- Snakk høyt og tydelig. Få ut deres tanker og meninger, utveksle erfaringer.
- Det er lov å kommentere på andres synspunkter og å stille spørsmål.

Slide 3

-

- Hvordan har koronapandemien påvirket ivaretagelse av de psykososiale behovene? Beskriv med eksempler.

- Hvilke psykososiale behov har hjemmeboende eldre med demens?

Slide 4

-

- Hva gjorde du konkret for å ivareta psykososiale behov hos COVID-19 isolerte hjemmeboende eldre med demens? Beskriv med eksempler.

- Hvilke områder måtte tilpasse eller justere for å ivareta psykososiale behov hos enkelte eldre med demens under isolasjon?
- Hvem har ansvar for ivaretagelse av psykososiale behov?
- Opplevde dere noen etiske dilemmaer i tilknytning til det å ivareta psykososiale behov?

Slide 5

-

- Hvordan samarbeidet dere med pårørende eller sosiale nettverket til brukerne?

Slide 6

-

- Hvordan kan erfaringene deres eventuelt anvendes i forbedring av psykososial omsorg hos hjemmeboende pasienter med demens?

- Avslutning/oppsummering

Slide 7

Slide 8

Annex 2: Excerpt from the coding process (raw data)

Data	Codes
<p><i>On the question of how the pandemic affected the management of the psychosocial needs of isolated home-dwelling patients with dementia</i></p> <p>1: Some of the users with dementia have benefited from going to the activity center, for example. And if they were isolated, they were not allowed to go there. And if they only have that one activity in a week, it becomes too long for them to wait for the next time. It can have a negative impact on the psychosocial health in a way when one is not allowed to go out like they are used to and maybe it was difficult for them to understand why it was like that. It was difficult to explain to them.</p> <p>1: The dialog was also affected when talking behind facemasks. It was difficult to hear. Communication was disturbed, like, one cannot read facial features and it sounded like we're mumbling.. There were times when one had to write things down, but if the user had bad eyesight, they couldn't read.. I remember it as a very big challenge.. It ate up a lot of time, just putting the equipment on and off, and one got worried, surely, "I must not infect anyone". It was very stressful, really.</p> <p>3: I had one user who didn't really understand that it wasn't okay to go out. So, some of the neighbors phoned us and they were worried because they saw the users outside. I remember that it was difficult then. What one could do in that situation. The users live there, and it's difficult to sit there and monitor or guard what they do. I tried hard to explain to them that they shouldn't leave the house.</p> <p>3: We have some users living in care homes (omsorgsboliger), municipal homes (kommunale boliger), and several live in blocks and know each other. They all see when we come and visit a user in full PPEs. Sometimes, we receive questions we are not allowed to answer because of confidentiality. So, we couldn't put a signage on the doors as well or in other places.</p>	<p>Break from routines Activity center as crucial to psychosocial health Feeling isolated and uncertain Difficult to explain the restrictions Minimal activity options for users Users were locked up during the pandemic</p> <p>Communication behind PPEs was ineffective Workers finding ways to communicate by writing One challenge after another Using PPEs took a lot of time Time for PPEs could have been used for psychosocial measures Workers stressed out and worried</p> <p>Resistance towards infection control measures Users forgetting protocols perhaps Symptoms over pure resistance Confidentiality issues Restrictions controlled both users and workers Feeling hopeless and incapacitated Frustration A community issue</p> <p>A community issue Ethical dilemma wrt confidentiality</p>

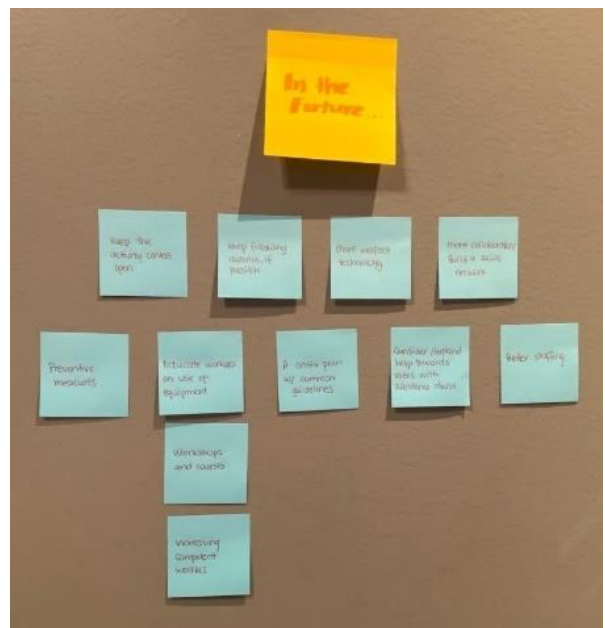
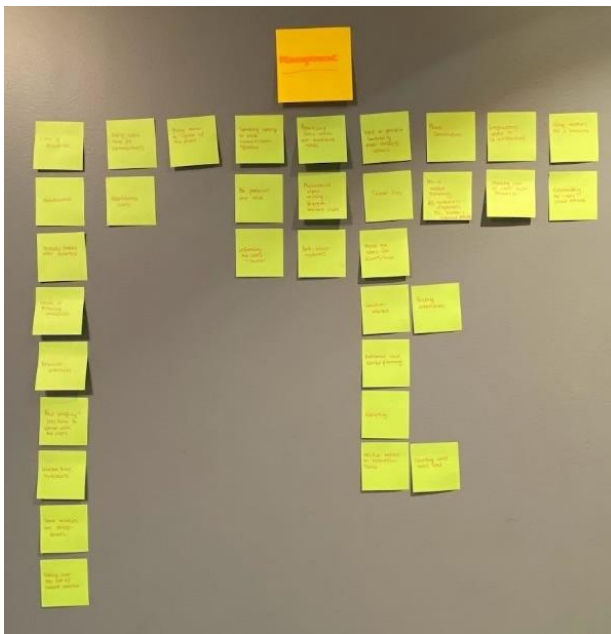
<p><i>On the question of managing the psychosocial needs of isolated home-dwelling dementia patients during the pandemic</i></p>	
<p>2: We didn't do much concrete measures because we didn't have the capacity.. Concretely, to manage them. Because.. For those in isolation, we were not permitted to be with other users.</p>	<p>Lack of resources Hopelessness</p>
<p>1: Maybe they underestimated the importance of activity centers. .. I remember that I tried to use some extra time for conversations and I tried to make the ambiance lighter. I remember calling myself an Easter chicken when I arrived in a yellow costume, and did something funny. And I tried to be (speak) as clearly as possible.</p>	<p>Activity centers were essential Using extra time for conversations Using humor to lighten up the mood Speaking clearly to make communication effective</p>
<p>2: There wasn't too much we could do then, because we felt like we were with bounded hands and feet. We had to double the visiting time, because we spent much time. We had to be two people working, one in the clean zone and the other in the dirty zone. We had to help each other do the things correctly, right, that stuff were removed properly to avoid transmitting the infection further. It was resource-intensive.</p>	<p>Hopelessness Hassle in following procedures Resource-intensive</p>
<p>4: What I'm thinking about is staffing at work. Because it's difficult in a way. First, you get a message that you go to an infected user and do your assignment, and then, you should leave as fast as possible to avoid getting infected. So, I think that the psychosocial aspect was, in a way, gone. Actually, it was the basic needs that were of utmost importance then for home care services.</p>	<p>Few staffing = less time to spend with the user Limited time, restrictions Psychosocial aspect missing Prioritizing basic needs over emotional needs</p>
<p>5: I had the same users in a row, which added up to security. They recognized the voice and the gestures and such. So there was a bit of security there. .. To make sure that they see our eyes. .. Otherwise, we were just an object to them.</p>	<p>Tried to practice continuity Make the users feel secure</p>
<p>6: Instead of physically going to the user's house, we called. We called and said, 'Hi, have you taken your medicines?' And you know, it's anti-social. It wasn't what the users wanted. .. I think that it's important that we are nice and pleasant towards the users. Because that little period of time when we visit, might make the user's day. If we come in mad or angry, the opposite things happen.</p>	<p>Phone consultations Anti-social methods Tried to be pleasant and nice</p>
<p>7: I think that everyone became better at evaluating what a certain user needs. We were</p>	<p>Positive impact on worker's evaluation skills Charting what users need</p>

<p>very generous with time spent with the users. .. If I used a little more time to teach someone to do things on his/her own, for example, putting on stockings, using helping tools, or preparing meals, easy ones.. The user had his/her own resources. It doesn't mean that we will withhold ourselves completely, but that we will be better in empowering the patients to do more things independently.</p>	<p>Empowering users to be independent Making use of users' own resources</p>
<p>4: The relatives needed to be informed, and they helped out. .. Oftentimes, they say, 'you can leave, and we will take care of this'.. There was also a bit of resistance against COVID-19' existence. It was like, they didn't think that the whole COVID thing was special. There were relatives who would say, 'Why do you have facemasks on?' It was very special, but it didn't make the situation better, actually. .. They say, 'we are deniers for COVID.' .. We think that it wasn't really about them. It's about the patient and taking care of them. .. They go without facemasks, like it was a joke. COVID is a joke. It was very special.</p>	<p>Information is crucial Some relatives are COVID-deniers</p>
<p><i>On future improvements</i></p> <p>1: I think that if a new pandemic comes, they should consider not shutting activity centers down, unless it becomes strictly necessary. It is an important service for at least those with dementia, and actually to all patientgroups. Because there many who are lonely and is feeling isolated.</p>	<p>Keep activity centers open</p>
<p>1: It is important, for example, specially for users with dementia, to follow the same routines at the exact same time. Because a deviation can lead to delirium. If there's a change or something. I've experienced it happen, although it was a change in the environment and routines that served as trigger factors.</p>	<p>Keep following routines if possible</p>
<p>1: More technological tools. That every one was given a screen device when the activity center was shut down. Make it obligatory. .. As a supplement.. I don't know if there are many users who were granted allotted time for conversation.</p>	<p>More welfare technology</p>
<p>2: We shouldn't think that home nursing care has the capacity to emplace ourselves at all times. We should collaborate with every one, the doctor, support contacts, activity centers. Relatives and</p>	<p>More collaboration Build a social network</p>

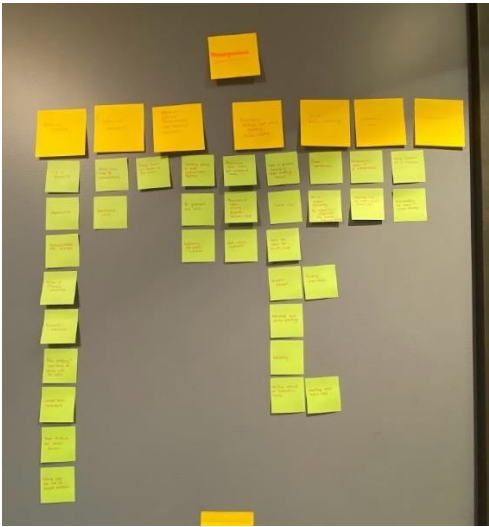
<p>friends, neighbors, family, that one helps in contacting others. Or build a social network, if we cannot take the role ourselves.</p> <p>4: I also think that maybe, the workplace should make a bit more adjustments, if they want people to have competence in different areas, for example, the psychosocial. They should send more workers in workshops, get more experience to manage it better. They can save economically, actually.</p> <p>5: We can make individual plans for each user. Because they have different needs. Even if they have that same diagnoses, they're still unique, like other patientgroups. We can make individualized plans on how we can follow up on the psychosocial aspect.</p> <p>6: More hands, to say so. Right. .. We have had days with many absences and we were exhausted.</p>	<p>Sending workers to workshops and courses Increasing competent workers</p> <p>Individual plans for each user Charting the user's psychosocial needs</p> <p>Better staffing</p>
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Annex 3: Code clustering and mapping (pictures)

1. Initial clustering



2. First mapping with initial themes



3. Second mapping



Annex 4: Developing themes (overview)

Initial themes (overview guide):

Psychosocial welfare management of COVID-19 isolated home-dwelling elderly with dementia		
<p>Homecare workers had varying views and understanding of the term ‘psychosocial well-being’ and its management, as well as to whose responsibility it was before, during and after the pandemic.</p> <ul style="list-style-type: none"> • Activity centers and its function on psychosocial health was emphasized • Relatives were either heavily involved or not at all • Psychosocial well-being as a collective responsibility • Administration and government as deciding factor • Homecare workers have had a major role in identifying users with psychosocial health problems • Psychosocial needs not prioritized 	<p>Homecare workers met ethical and practical issues and dilemmas: Factors that served as context for the management of psychosocial needs.</p> <ul style="list-style-type: none"> • The pandemic as a community issue and a public health concern / Lack of privacy in communal settlements • Committing deviations from guidelines and routines to meet users’ need for social companionship and physical nearness • Felt pressured: Torn between the sense of duty/obligation and their personal safety • Frustration over work organization, changing routines, and users who refused to follow guidelines • Felt stressed out, worried, hopeless and incapacitated due to restrictions and different prioritization guidelines • Healthcare workers admitted to using lesser time with the users • Use of PPE increases the risk for making medical mistakes like wrong medicine dosage and administration • Use of PPEs was a barrier to communication, establishing trust and performing tasks 	<p>Management of psychosocial needs amongst the user group required skills and competence.</p> <ul style="list-style-type: none"> • Knowledge of dementia is crucial in analyzing changed behavior and coming up with creative solutions • Effective communication and optimistic behavior • User empowerment • Prioritizing, advanced and careful planning, and being solution-oriented • Use of welfare technology and phone consultations • Collaboration with relatives and other healthcare professionals <p>Homecare workers wanted improvement and change in the future.</p> <ul style="list-style-type: none"> • Make exceptions and keep the activity centers open • More welfare technology • Build a social network for the users • Consider users with substance abuse + dementia • Focus on preventive measures and contingency plans/Create a crisis plan with common guidelines • Repetitive practice on the proper use of equipment • Better staffing/more competence at work

Annex 5: Used statements from the FGIs

Statements from the interview in Norwegian	English translation
<p>4: .. Å ha noen, på en måte, ved siden av seg, liksom, å oppleve trygghet, og å ha noen å prate med, sånn ting.</p> <p>7: Det er jo veldig individuelt fra person til person. Vi har jo de som er avhengig av nesten å få klem hver dag, til de som helst vil ikke se andre mennesker. Holde med de som var på TVen. Så du har jo et veldig vidt spekter av behovene er, da. Mener jeg i hvert fall.</p> <p>1: Jeg tenker jo kanskje med en gang da at noen av de med demens har jo veldig godt av å komme på dagsenter, for eksempel da. ... Og at det kan ha en negativ innvirkning på det psykososiale ved at man ikke får lov å komme ut som de er vant til og kanskje var det vanskelig å forstå hvorfor noe sånn, at det kunne ha det vanskelig å forklare kanskje.</p> <p>3: Det er jo allerede, også, det er jo på en måte ganske vanskelig fra før, så når COVID kom, så ble det på en måte egentlig bare lagt på hyllet.</p> <p>1: Det er jo dagsenter på en måte, som har hoved, ... Det har besøkshund også. Det du kan få av alt som ble på en måte satt på vente. Og det er jo begrenset hva hjemmesykepleien få gjort. Vi er jo der å prate, men det er jo da begrenset hvor mye vi kan sitte og prate.</p> <p>6: Det er jo vi. Det er jo vi som jobber i helsevesenet. Vi som kjenner de, på en måte, pasienten best. Så når jeg kommer inn hos en pasient, jeg ser en pasient som har alltid vært ute, og som alltid har vært, på en måte, ute og har vært veldig sosialt, og plutselig, på en måte, har blitt, ikke sant, at pasienten ikke kunne komme seg ut på egen hånd. Så er det viktig at vi tenker, 'ok, er det aktuelt for den pasienten her at skal komme seg på dagsenteret' .. Så det er vi, vi som jobber i helsevesen, så er vi som har ansvar for sånne ting.</p>	<p>4: «<i>It is to have someone, like, beside [you], like, to experience security, and to have someone to talk to, those things.</i>»</p> <p>7: «<i>It's very personal, different from person to person. We have several who are almost dependent on getting a hug every day, and those who would barely see other people. They just limit themselves with those on TV. So you have at least a wide spectrum of needs, I think.</i>»</p> <p>1: «<i>I think maybe, right away, that some of them with dementia have benefited from going to the activity center, for example. ... And it can have a negative impact on the psychosocial [well-being], in a way that one is not allowed to go out like they are used to, and maybe it was difficult to understand why it was like that, (and) that it was difficult to explain to them, maybe.</i>»</p> <p>3: «<i>It was already, also, it's quite difficult from before. So when COVID came, so it was, in a way, put away on a shelf.</i>»</p> <p>1: «<i>It's the activity center, in a way, which has the main (responsibility), ... It has visiting [therapy] dogs as well. The place where you can get something of everything was in a way put on hold. And there's limitation to what home nursing care can do. We are there to talk, but it was limited how long we can sit there and talk.</i>»</p> <p>6: «<i>Well, it's us. It's us who work in the health care system. We who know the patient best. When I come and visit a patient, I see a patient who has always been outside, and who always had been social. And all of a sudden, that patient couldn't go out alone. It's important to think, 'ok, will it benefit the patient to join the activity center?'. So, it's us, us who work in the health care sector, who have the responsibility for such things.</i>»</p>

5: Ja. Det er på A.. øvre hold, at dem kan gjøre litt unntak på svakere grupper, for eksempel. For det var ikke så mye vi følte at vi kunne gjøre, når vi var på en måte låst i restriksjoner. Vi kunne jo ikke lage våre egne regler. Reglene var jo satt. Sånn at det.. Det burde komme fra de som setter reglene, på en måte. Regjeringen. At på en måte, svakere grupper skal tas vare på. .. Det er jo et kollektivt ansvar, vil jeg jo si, det er jo ikke noen som skal ha det ansvaret, på en måte. Det er jo oss som jobber, ledelsen, det er .. Vi må jo jobbe sammen om det.

7: Det er som jeg sa om ----- som trengte en klem for å bare roe seg ned, rett og slett. Eller en hånd for å kjenne, kjenne menneskelige kontakt da. Det er jo mange som ikke ble tatt på gjennom hele pandemien nesten, fordi de klarte seg selv med stell og veiledning, så det, du trenger ikke å ta på de. ... Men de som klarte seg selv og ikke, ikke hadde menneskelige kontakt på så lang tid, det, du merket på en måte hos noen lett desperasjon nesten. At det å bare få en klem eller holde en hånd eller. I noen tilfeller så ble det jo så ille at du gjorde det jo for det var det behovet den pasienten hadde der og da. Da var den nesten viktigere enn tanken på at kanskje jeg har noe smitte eller at den pasienten har noe smitte eller.

7: Jeg har vært bort i flere som har vært veldig imot selve testingen. I hvert fall med den dyp nese prøven. Hvor jeg måtte bruke lang tid på forhånd og prøve å forklare, så hadde de jo gjerne glemt det inn det jeg hadde åpne q-tipsen jeg skulle bruke, den testing utstyret da. Og så ble de jo redder når de merket at det kom opp i nesen, selv om jeg hele tiden prøvde å si hva jeg drev med, så.. Begynte å kaste på hodet og så bare sånn, 'stopp, stopp, nei, jeg vil ikke'. Jeg kan jo ikke. Det var ikke noe tvangsvedtak på det heller. Jeg kan ikke sette meg på det og ta den testen heller.

5: Du mister jo kommunikasjonen fordi dem leser jo ofte på leppene og dem skal ha hele inntrykket. Når det kommer til, eller med sansene, så det er jo, på det blikket og leppene og alt, skal vi jo, liksom, harmoni og kroppsspråk ... Og så ble vi bedt at man skal kompensere, og da ble det gjerne med å skrike, og så hører dem bare skriking og ikke ord. Sånn at dem ble jo mer utrygge, mange, redder, ikke minst.

5: «It's on A.. the upper level, they can make exceptions for the weaker groups, for example. We felt that there wasn't much we could have done, when we were like locked in restrictions. We couldn't make our own rules. Rules were already made. Like, they should come from those who make the rules. The government. Like, the weaker groups should be taken care of. .. It's a collective responsibility, I'd say, there's no one who wants that responsibility, in a way. It's us at work, the administration, it's the.. We have to work together for it.»

7: «It's like what I said about (a user) who needed a hug to calm down. Or a hand to hold, to feel human contact. There were many who were not held through almost the whole pandemic, because they could manage on their own, so you didn't have to go to them. ... For those who could manage on their own and didn't have physical human contact in a very long time, you noticed somehow that there's a bit of desperation. Just to have a hug or to hold hands. In some cases, it was so bad that you just do it because it was what the patient needed at the moment. It was almost more important than the thought that maybe, I have the virus or that the patient has it.»

7: «I've encountered several who were very much against testing. Specially with the deep nasal swab test. Where I had to use a long time in advance to explain, but then, they've forgotten all about it right after you opened the swab kit. Then they get terrified when they feel it going up inside the nose, even if you explain the whole time what was going to happen. They start banging their heads and say, 'stop, stop, no, i don't want to'. I couldn't continue. There was no decision on use of force there. I couldn't do it and take the test.»

5: «You lost the communication aspect because they often read the lips and they would use the entire expression. When it comes to, or with the senses, it was like, with the gaze and the lips and all, like the harmony and body language. ... And so we were asked to compensate, and that's by shouting. But then, they only hear the loud sounds and not the words. Such that they become more insecure, many were afraid, to say the least.»

7: Og så, synes det var vanskelig den situasjonen hvor vi informerte pårørende om at brukeren er i karantene, og så de kom a likevel på besøk. De dro a likevel mot brukeren. Eller hvis jeg var hjemme hos en bruker som ikke var i karantene, ikke var smittet, det var liksom kun de vanligere restriksjoner vi fulgte. Og så sier pårørende midt i besøket at 'ja, jeg har jo korona'. Da. Noen ble jo både irritert som helsepersonell, men, 'hvorfor dro du da og besøket en eldre person hjemme, hvis du vet du er smittet, selv om du ikke har symptomer. Og hvorfor utsetter du meg for det'.

3: Så har vi jo en type som omsorgsboliger, kommunale boliger, flere bor i en blokk og kjenner hverandre, så ser dem jo at vi går til enkelte brukeren med fullt smittevernutstyr og da har vi kanskje noen spørsmål, vi kan ikke svare på med forhold til taushetsplikten, så har vi ikke mulighet å skrive lapp på verken på døra eller andre steder.

6: Vet du det som var der, at på en måte, at den selv-følelsen, at vi, når jeg er ble spurt om, ja, når det kom inn og 'ja, nå er det sykdom eller noe eller smitte, nå har vi ingen som kan jobbe', og så sittet jeg og tenkte, ok, hvis jeg sier nei, og du sier nei, og hun andre sier nei, og han andre sier nei, hvem er det som skal jobbe da? Og det er en pasient som sitter hjemme og virkelig trenger den hjelpen. Og så har jeg min egen familie også hjemme, og da måtte du på en måte, sette familien på sida. For egentlig for pasientene. Så det var veldig tøft, og det var mange av oss som hadde gjort det. At man setter familie på sida.

1: Jeg husker at jeg prøvde på en måte bruke litt tid for samtaler da og prøvde å gjøre stemningen litt lyst da. Jeg husker jeg kalte meg selv som påskekylling da, da jeg kom der i gul drakt liksom, og gjorde litt morsomt da. Ja. Og prøvde å bruke litt tid på å være så tydelig jeg kunne da, å bruke litt ekstra tid for samtalen med første jeg har kledd på meg på en måte. Å være der. Men det er.. ... Det er jo viktig, for eksempel, spesielt for demens, å holde rutiner på samme tid. For at det er brudd på rutiner kan føre til delir. Hvis det blir bytte eller sånn, ja. Jeg har opplevd at det har skjedd, men det er miljøforandring og rutiner kan være utløsende da.

7: «I think that those situations were difficult, when we informed the relatives that the patient had to be in quarantine, and so they still came to visit anyway. They came anyway. Or if I was homevisiting a user who's not isolated, not infected, just following the normal restrictions. And the relatives say in the middle of the visit, 'yes, I have corona infection'. Then. Some were just irritated as a healthcare worker, like, 'why did you come here, to an elderly person, if you know you are infected, even if you don't have symptoms? And why are you exposing me to the virus?'.

3: «We have some, like, care homes (omsorgsboliger), municipal homes (kommunale boliger), several live in a block and know each other, so they see that we come and visit a user in full equipment, and maybe we received questions we couldn't answer because of confidentiality, so we have no chance to write a signage on the door or other places.»

6: «You know what, like, that inner feeling, when we were asked if we could work, yes, when they come in and say, 'yes, we have absences because of illness or infection, we have no one who can work', and I sat and thought, ok, if I say no and you say no and she says no, and he there says no as well, who's going to work then? And there's that patient sitting at home and really needing your help. I also have my own family at home, and you had to, like, put your family aside. For the patients really. So it was very tough, and many of us in home care had done that. To put your family aside.»

1: «I remember that I tried somehow to use a little more time for conversations and tried to make the ambiance lighter. I remember calling myself an Easter chicken, when I arrived in yellow costume, and did something funny. And tried to spend some time to be as clear as I could, to use a little extra time for the conversation with the first (second) I put (protective) clothes on me, in a way. To be there. But it is.. ... It is important, for example, specially for dementia, to keep the routines at the exact same time. Because a deviation can lead to delirium. If there's a change or something, yes. I've experienced it happen, but it was change in the environment and routines that can be a trigger factor.»

<p>8: Ringetilsyn er jo et skritt videre til å avslutte besøk, for høres det til hjemmetjenesten. Vi går fra å ha et besøk og gjøre en oppgave og så går vi til ringetilsyn, for da er vi jo begynt å trappe ned, og så alle er ferdig på en måte.</p> <p>9: Egentlig så vi laget en plan, for eksempel, begrenset besøk, noe sånt. Så det er de brukerne med på det da, også fastlegen. At det ikke bli farlig for helse og sånt da. ... At det ikke vi som bestemmer alt på hva slags tilbud eller besøk de skal avslutte eller begrense, noe sånt. Så det er med legen og brukeren selv.</p> <p>6: Ja, det er både-og, for å si det sånn. Det er forskjellige fra pårørende til pårørende. Noen er veldig flinke, og noen prøvde, sånt, at ok, holde seg unna hjemmesykepleier, da 'vi holder oss unna', ikke sant. Det er sånn og'. Så.. Men det meste av dem, så sier, synes jeg dem er flinke å passe på. Så ja.</p>	<p>8: «<i>Phone consultations are actually a step further into ending visitations, it belongs to home care services. We go from visiting and doing tasks to phone calls, for we've started to reduce the visitations, and so everyone is finished in a way.</i>»</p> <p>9: «<i>Actually, we made plans, for example, limited visitations. So, the users agreed to that, as well as the GP/doctor, that it's not going to be a health hazard. ... So it wasn't just us deciding over which services or visitations or restrictions, like that. It's also conferred with the doctor and the users themselves.</i>»</p> <p>6: «<i>It's and-or-or. It's different from relatives to relatives. Some were very good, and some tried to, okay, keep their distance from home care, and said, 'we're keeping our distance', right. It's like that. So.. But most of them are good and took care of things, I guess. So yes.</i>»</p>
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