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# Social needs in a nursing home context

How are social needs and social care understood within a nursing home context?

# Master's thesis in International Social Welfare and Health Policy Oslo Metropolitan University Faculty of Social Science

#### **Abstract**

This thesis explores how social needs and social care are understood within a nursing home context. Studies suggest that elders in nursing homes are susceptible to loneliness. Newer political aims are to combine caregiving from family members and public health services to ensure extensive care of elder's social needs, but there is a lack of conversation about how this collaboration should come to place.

This thesis seeks to explore the research question based on semi-structured interviews, as well as follow-up interviews, with six family members of nursing home residents. The analysis is inspired by interpretative phenomenology, social constructionism and symbolic interactionism. Family members' understanding of social needs and social care is attended to as created and influenced by the interactional interview process. The analysis explores family members' accounts and their underlying preconceptions. Additionally, how the accounts legitimize or create different understandings for the concepts of social needs and social care.

The results suggest that social needs are a broad concept with both a general and a personal dimension. They also suggest a downplaying of social care in favor of healthcare within the nursing home context. This argues for measures for social care to take into account social needs as both general and personal to ensure its extensiveness. Further research is needed on how to care for general and personal social needs in a declared strategy, and how to incorporate this to a functional collaboration between the caregiver roles. Further research on the perspectives of the nursing staff and the nursing home resident would give beneficial insights and is encouraged.

#### Acknowledgements

This master thesis is the results of two extraordinary years of study. The international aspect of the master degree caused for interactions with students from different cultural-and academic backgrounds, that in many ways broadened my knowledge and perspectives on health- and social political issues.

Firstly, I would like to thank my supervisor Erik Børve Rasmussen at Oslo Metropolitan University, for giving comprehensive and encouraging guidance throughout the process of me writing the thesis. I would also like to thank the members of the science group WATT at Oslo Metropolitan University for welcoming me into their group as a master student, and inviting me to instructive seminars. This created a basis of inspiration and motivation to write my master thesis during a period of lock-down due to the corona pandemic. With that said, I would also like to place a thanks to those working from their home offices for maintaining normality at the universities during the pandemic. At last, I would like to place a thanks to my family and friends for always believing in my abilities and cheering me on.

Oslo Metropolitan University, Faculty of Social Science Oslo 2021

# Table of contents

1.	Introduction	6
2.	Theoretical view	10
3.	Method	12
	The procedure	13
	Ethical clearance and further implications	16
4.	Results	18
	How are social needs understood?	18
	Social needs as general needs	19
	Social needs as personal needs	22
	What position does social needs and social care have within a nursing home context?	26
	Healthcare prioritized before social care	26
	Person specific care as an ideal, and not an expectation	29
	What position does social needs and social care have among the family members?	33
	Visitation as work	33
	Working together with the nursing staff to ensure elders social needs, or?	35
5.		
	Social needs as both general and personal	38
	Implications for social care: Who and How	38
	The nursing home as an extensive care facility	40
	Family members as contributors of social care	42
6.		
Re	eferences	46
A	Attachment 1: Interview guide	
	ttachment 2: Information letter	
Δ	ttachment 3: NSD: Reporting form/Meldeskiema	54

## 1. Introduction

What happens when we grow old? Our health deteriorates, either our physical health, cognitive health, or both. This often includes loss of hearing or sight, reduced mobility or a dementia disorder. Many outlive their friends or partner, retire from work or other activities, and lose energy for social engagement. A social consequence of old age is therefore an increased likelihood to experience loss of social relations. Many studies are concerned with these factors, and how they make elders more susceptible to loneliness (Hagan, Manktelow, Taylor & Mallett, 2014; Slettebø, 2008; Mjørud, Engedal, Røsvik & Kirkevold, 2017; Støren & Todorovic, 2019). Which can be understood as the unpleasant experience that occurs when a person's network of social relations is deficient in some important way, either quantitatively or qualitatively (Perlman & Peplau, 1981, s.1). Studies suggest that loss of close relations, deteriorating health and retirement to nursing homes all has the potential to induce loneliness among the elder population (Hagan et al, 2014; Slettebø, 2008; Mjørud et al. 2017; Støren & Todorovic, 2019; Barstad & Sandvik, 2015). Furthermore, that loneliness among elders is correlated with reduced physical and mental health, as well as greater risk of mortality (Hagan et al, 2014). These findings lay the grounds for worrying about elder's sociality, and cause for political measures to reduce loneliness in the elder population (Meld St. 15, 2017-2018).

In Norway, approximately 16 percent of elders in their sixties, and 63 percent of elders in their nineties, spend their last days living in a nursing home (Statistisk sentralbyrå, 2020). Within the nursing home, the nursing staff has the task of supervision over the elders, and to make sure that they are properly fed, bathed, and that they feel well. It can be argued that elders in a nursing home have a more satisfying social life compared to those living alone, as they have other nursing home residents and the nursing staff present, whom they can socially engage with. However, in a study by Mjørud et al. (2017), nursing home residents described living in a nursing home as a life of isolation, uncertainty and fear. A study done by Slettebø (2008) found living in a nursing home to be described as a "safe but lonely" experience. These studies suggest a need for improvement of social care practices within the nursing home. I would therefore argue that social needs and social care within a nursing home context is an important topic on which we should seek deeper knowledge.

Elders are subject to changes that impacts both their physical and cognitive health. This makes them dependent on resources in others to function properly. When loneliness occurs in the younger age groups it is often treated by looking for resources within the person itself. For

example practicing social skills (Cacioppo, Grippo, London, Goossens & Cacioppo, p. 242). Elders' deteriorating health can cause irreversible effects on their cognitive states, which might impact their ability to cope using their own inner resources. This makes them dependent on others, such as family members or the nursing home staff, to prevent or minimize loneliness. This causes a need for collaboration between the nursing staff and the elders' family members in order to prevent or minimize feelings of loneliness.

The last years, there has been a focus on the potential resources in family members in improving the elders' lives in nursing homes. A political document from 2017-2018 describes family members as "an irreplaceable resource, both for their loved ones, but also for the healthcare services." (Meld. St. 15, 2017-2018, s.46). Studies suggest that family members can contribute to a better psychosocial environment for their elders, and that strengthening the family's involvement has the potential to promote residents' health in nursing homes and further improve the nursing home service (Nakrem & Hynne, 2017; Rognstad, Sagbakken & Nåden, 2014). However, studies have framed it to be an issue of family members experiencing limited inclusion as a resource. Findings suggest that many family members experience a transition from being an active caregiver for their elder while they still live at home, to someone who is not involved or familiar with their elders' needs in the nursing home (Haugland, 2012; Rognstad et al, 2014; Nakrem & Hynne, 2017).

Norway has a long tradition of leaving the state and municipal agencies responsible for caring for the more vulnerable of the society (Kalve, 1985; Prop. 1 S, 2020-2021). Therefore, the policy for elderly care places great demands on social and health professionals to promote services concerning both elders' physical and mental health (Halvorsen and Stjernø, 2008; Meld. St. 15, 2017-2018). Where does this leave us in the question of family members as a resource? For many years, family members have traditionally cared for their elders. This care has often included everything from bathing, feeding to having supervision over their elder. Often with the goal to enable them to live at home longer, and to prevent their elders from retiring to nursing homes (Kalve, 1985).

Newer political aims are to combine caregiving from family members and public health services to ensure extensive care of elder's social needs (Jenhaug, 2018; Prop. 1 S, 2020-2021. A political reform wants to "facilitate closer collaboration on common tasks between family members and the healthcare service" (Meld St. 15, 2017-2018, s.10). However, there is a lack of conversation about how this combination should come to place. Including lack of communication about power sharing and partnership development between the nursing staff

and the elders' family members (Jenhaug, 2018). Studies suggest that family members often feel confusion about their caregiving role and experience a lack of communication with the nursing staff. Therefore, it can be argued that the collaboration between family members, the nursing home staff and the elder are not reaching up to its potential (Nakrem & Hynne, 2017; Jenhaug, 2018).

Why is the collaboration for social care still a task at hand, and not a task fulfilled? Collaboration for social care is not distressed within The law on municipal health and care services, nor the regulations for nursing homes. Meanwhile, it is distressed that the healthcare services have a duty to ensure collaboration with other healthcare services, the municipality, the regional health authority and the state in order to maintain quality of service. Yet, it is stated that the law om municipal health and care services aims to promote social security and prohibit social problems for the disadvantaged in society (Helse- og omsorgstjenesteloven, 2011, § 1-1 - 1-2, 6-1 – 6-6; Forskrift for sykehjem og boform for heldøgns omsorg og pleie, 1988). As some studies suggest that family's involvement can improve the nursing home residents' health, as well as improve the nursing home service, not including collaboration between family members and healthcare professionals within the regulations can be argued to be counterproductive (Nakrem & Hynne, 2017). Furthermore, measures taken to ensure quality of elders' social lives in nursing homes often include services carried out within the nursing home context. Examples are the offer of joint activities, excursions or arranged visits with volunteering visiting friends through an organization (Haugland, 2012). These are measures that do not include the family members as a recourse for bettering the elders' social life, and the collaboration between the nursing staff and the family members is absent.

The thesis sought to answer the following research question: **How are social needs and social care understood within a nursing home context?** The thesis took a step back from the issues of collaboration between the family members and nursing staff, and explored what social needs and social care is within a nursing context. This can potentially give beneficial knowledge for the issue of collaboration, as well as clarifying caregiver roles for social care.

As means to answer the research question, the thesis was guided by the following questions: (1) How are social needs understood? (2) What position does social needs and social care have within a nursing home context? (3) What position does social needs have among family members? The thesis took base in family members perspective by exploring what social needs is within a nursing home context, based on what the family members redeemed to be important to mention. Further research on the perspective of the nursing staff

and the nursing home residents, as well as more family members, is encouraged to provide more extensive knowledge on the matter.

The concepts used in the thesis are in need for clarification. This thesis uses the word nursing staff as referring to all the employees in the nursing home. For instance, health care professionals such as nurses, physiotherapists and the occupational therapists, but also other employees like the department manager. Family members refer firstly to the informants of the study, but also to relatives of nursing home residents. The concepts of social needs and social care were concepts being studied, as the thesis seized to capture how the family understand and make use of the concept of social needs and social care. Studying social needs was done to investigate means to prevent loneliness. Moreover, the concept of social care was used to investigate what the nursing staff and family members do to ensure that their elders' social needs are met, but also how they experience their caretaker role and its expectations, as well as the collaboration between the caregiver roles.

As means to answer the research question, I interviewed six family members testing out a newly developed device called KOMP, as part of the research and innovation project "Safe and simple point of contact with relatives". KOMP consists of a screen designed to facilitate both written and video communication, between analogue elders and their family members (No isolation, 2021). New technology has been suggested as a way to improve social contact between family members and nursing home residents. Studies suggest that video communication can strengthen the contact between the nursing home resident and their family members, induce cognitive support and understanding, as well as lessening depression and loneliness (Alnes, Berg, Krøvel & Blindheim, 2019; Schuster & Hunter, 2017). For this reason, video communication can contribute to making family members function as a resource. In this thesis, family members' experience with KOMP was used to tap into the family members understanding and positioning of social needs within the nursing home, as well as their perspective on collaboration of caregiver roles for social care. Their experiences can also be useful in further development of technologies and services to combat loneliness and ensure social needs of elderly in nursing homes.

The thesis proceeds as follows. I will further elaborate the means to which the research question was explored by describing the thesis' theoretical perspectives, as well as methodological approach. This is followed by a presentation of the results and its related discussion, ending in a conclusion.

## 2. Theoretical view

The research question will be explored by taking an explorative qualitative approach inspired by the micro-interactionist traditions of interpretative phenomenology, social constructionism and symbolic interactionism. In short, interpretative phenomenological analysis explores how informants make sense of their personal and social world by interpreting their experiences. The focus is to explore informants' subjective perceptions, and not to produce objective statements of an object or an event (Smith & Osborn, p.53). The same goes for social constructionism, where the understanding of an object or an event are constructed by human thoughts, rather than grounded in an observable, external reality. The thesis is therefore inspired by a relativistic position (Burr, 2015).

The thesis is also inspired by the perspective of symbolic interactionism. Within the tradition of Mead, people construct and negotiate identities for themselves and others through their everyday social interactions with each other (Burr, 2015, p.222). Language is central to the construction, as it is seen as reflecting a system of socially shared symbolic meanings, often taken for granted by the social actors. Language can therefore create, maintain or legitimize different understandings of social needs and social care. Therefore, human thoughts are seen as uttered in language that reflects family members' experiences (Burr, 2015).

The phenomenological, constructivist and interactionist perspective was used to study how family members understand social needs and social care within a nursing home context. Therefore, social needs and social care were explored according to their social character. The same goes for other categories that the analysis touch upon. For instance, individuality, identity and health, that were central in the family members discussions of social needs and social care. This means that the ruling definition of social needs and the other categories, and the way these should be attended to, are not facts to be found in nature but social phenomena, subject to negotiation, collaboration and contestation between social actors. Specifically, as done by how family members talk about their experiences regarding social needs and social care (Berge, 2003; Johannessen, Rafoss & Rasmussen, 2018).

Family members' accounts was treated as an expression of their experience, as their attempt to make sense of the world as it is right now. What the family members think, state and feel was attended to as connected, even if such a connection can be contested by how people often struggle to express their thoughts and feelings (Smith & Osborn, 2007, p.53). Family members' experience are both shaping and being shaped by social situations, and

social interactions. I was interested in how the system of socially shared meanings influences the family members' experiences and constructed accounts. Therefore, the accounts were also an entry to explore these socially shared meanings. Thus, the thesis used family members' experiences to contract how social needs and social care as understood and positioned within a nursing home context (Smith & Osborn, 2007, p.53; Dennis & Smith, 2015).

Inspired by symbolic interactionism, I was interested in how understandings of social needs and social care as subject to social negotiations and influenced by the social situation. Attention was directed towards the interactive interview situation between me and the family members. I was therefore a part in the construction of the experiences I later explored. For this reason, I strive to be transparent in the way the interview questions were asked.

The analysis took base in an interpretation of family members' experiences, and how they reflect a system of socially shared meaning. In other words, the focus was to capture how family members' construct social needs and social care as concepts, as done in an interactional interview situation. This was done by studying family members' choice of words and phrasing. What seems to be going on, from family members' perspective, was used to study what these statements achieves during the interview process. Moreover, the analysis explored the relationship between different statements in the text, and how they legitimize or create different knowledge on how social needs and social care are understood. I also sought to explore the accounts' underlying preconceptions, as often taken for granted by the social actors (Berge, 2003, p.26; Smith & Osborn, 2007, p.53). The positioning of social needs and social care within the nursing home was explored by studying family members attribution of responsibilities and expectations to the caregiver roles regarding social care (Bergström & Boreus, 2005, s.308-314).

The data material reflected what the family members recon to be of relevance to mention in a conversation about elders' social needs in a nursing home context. Moreover, how family members find it appropriate to talk about different topics, actors and instances regarding social needs in a nursing home context. This can give information on current cultural norms and positioning of the caregiver roles regarding social care (Holstein & Gubrium, 1995, p. 2).

What the family members experience will have a conditional value in itself. This is because how these experiences are uttered get its own meaning due to the interactional premises of the interview process, which gives the concept of social needs specific features, and a specific position (Berge, 2003, p.30; Smith & Osborn, 2007, p.53). The micro-

interactionist traditions helped to shed light on what social needs is within a nursing home context, as seen from the perspective of family members of nursing home resident

# 3. Method

This research question sought information on how social needs and social care is understood and positioned within a nursing home context. I wanted to engage in the experiences and understandings of those involved in the elders' social needs in nursing homes. The information was gathered by using a qualitative approach, consisting of interviewing six family members of nursing home residents. I did semi-structured interviews with each family member, lasting one to two hours, as well as a follow-up interview approximately one to two months after the first interview. The purpose of the follow-up interview was to capture family members experience using KOMP, as a way to further explore how they experience their caregiver role regarding social needs. The time of the follow-up interviews were therefore set according to when the family members had gathered one to two months of experience using the KOMP device. There was one drop-out due to death of one nursing home resident. In conversations with the family member, I chose to not pull through with the follow-up interview out of respect for the informant, resulting in five follow-up interviews.

For this study, the aim was to gather detailed data on family members' perceptions and understandings of social needs and social care, rather than gathering data to make general claims for larger populations. For this reason, I interviewed six family members to ensure a fitting amount of interview material, as well as enabling time and resources for doing deeper and more detailed interviews. However, the perspective of more family members would provide beneficial insights. The follow-up interviews allowed for further elaboration on the topics mentioned in the first interview, using KOMP as a way to tap into family members' understandings of their own caregiving role as well as the nursing staffs' (Magnusson and Marecek, 2015; Smith & Osborn, 2007, p.55).

The semi structured interviews were a means to capture in detail how family members perceive and make sense of their experiences. Furthermore, their thoughts, ideas and understandings on social needs as carried out, created and/or maintained in the interview process. Semi structured interviews allowed for flexibility in the family members responses, making them contributing by guiding the interview into topics they deemed to be of

relevance. The interview process is attended to as an interactional dialogue between me and the family members, where interview questions and the family members responses were mutually modified after each other, enabling me to follow up on interesting topics which arose. The findings are therefore a product of the conversation between me and the family members. This form of interviewing made it possible to get as close as possible to the family members understandings, without being led too strongly by the interview questions.

(Holstein and Gudbrium, 1995; Smith & Osborn, 2007, p.57). I asked family members directly about their thoughts, understandings and opinions on the topic of elders' social needs, as well as their and the nursing staffs' caregiving role. This created room for further reflections on how these thoughts, understandings and opinions come to place, and their implications for how social needs and social care are attended to within a nursing home context.

The interview situation was a part of the creation of the data material, and reflects the family members' perspective. What about the perspective of others social actors, such as the nursing staff or the nursing home resident? Family members get their relevance for the study based on their often close presence in their elders' social life, as well as their wanted presence as a resource for the nursing home by politicians (Meld. St. 15, 2017-2018). Furthermore, the corona pandemic made the family members the easiest way in. The nursing staff has experienced enhanced time pressuring conditions during the pandemic, resulting in challenges with creating and maintaining contact with them (Monsrud, 2020; Andreassen, Olsen & Hager-Thoresen, 2021). The elders often reduced cognitive states also argues for the decision to interview family members. However, the perspective of the nursing staff and nursing home residents would create beneficial insights for the understanding social needs. Further research on nursing staffs' and nursing home residents' point of view are therefore encouraged. In the meantime, the restrictions due to the corona pandemic, which often entailed lock-downs and reduced social engagement, might have made family members more aware or susceptible to things they might otherwise have overlooked or taken for granted. This makes them a valuable source of information for exploring the research question.

# The procedure

I am writing this thesis as a part of the science group WATT (welfare access through technology), who explores the relation between ideology and welfare technology targeted at socially isolated people (OsloMet, 2020a). My connection is to their sub study on KOMP

called "Safe and simple point of contact with relatives", which entails research on loneliness-reducing technology in elderly care (OsloMet, 2021b). Therefore, the recruiting of family members was done through this sub study. Six interview invitations were sent by mail to family members already enrolled in the KOMP-project. Those responding yes were adult children or partners, of different nursing home residents. Two of the six were partners and four were children. The children of the nursing home residents were at the age of 30 or older, and two of the children was the eldest of their siblings. Two family members were males, and four were females. Each family member was interviewed for approximately one to two hours, and enrolled in a shorter follow-up interview one to two months later with a duration around 30-60 minutes. I experienced one drop-out at the follow-up interviews due to death of one nursing home resident, which I chose to discard from the follow-up interviews to show respect. For this reason, eleven interviews were conducted in total, based on six family members.

The interviews were conducted during the corona pandemic, where the restrictions resulted in eight video-call interviews, two telephone interviews and one interview in person. The interview guide consisted of three parts. One on the relationship between the family member and their elder, another on the relationship between both the family member, the elder and the nursing staff, and a more general part about family members' thoughts on the caretaking of their elder's social needs. Examples on interview questions asked are *How* would you describe the relationship between you and the nursing home resident?, How would you describe the relationship between you and the nursing staff? and Could you tell me about how you experience your role as a family member of a nursing home resident? The focus was on developing interview questions that are meaningful to the family members, and interview questions that allows them to give answers reflecting their experiences and understandings of social needs. The interview guide was therefore used to guide the conversation towards topics of relevance for the research question, allowing for the order of the questions and the topics to adjust after the family members accounts. The interviews were therefore partly guided by the family members themselves, where I noted down which questions that had been answered, what I would like for them to elaborate more on, and which questions that remained to be answered. This allowed for family members to show me what was important for the understanding of social needs and social care, and not the other way around. My experience is that the interview was a pleasant experience, where the family members seemed comfortable and open. There was room for questions and further discussions on the interview topics,

enabling me to get further elaboration on topics I deemed interesting for the research question. The same experience goes for the follow-up interviews, that were conducted approximately one month after the first interview, and focused on family members' experience with KOMP and its possible contribution in improving the elders' social lives.

For this thesis, family members experience with KOMP was used as a means to gather information on the family members understanding of social needs and social care, as well as their role regarding social care within a nursing home context. Therefore, family members experience with KOMP as a device was therefore not of interest for the research question per see. To gather information of interest, I asked what they thought was expected from them in the process of testing out KOMP as a communication device, and used this to reflect upon what seems to be the position of social needs based on family members statements. What does the nursing staff communicate to the family members by handing out KOMP? What implications does this have for the caregiving role of both the nursing staff and the family members? Thus, the elders might have to rely on the nursing staff to support their communication efforts (Schuster and Hunter, 2017). This leaves for situations where family members and nursing staff's caretaking roles interact. Creating a possibility to further discuss on social care for nursing home residents are divided between the nursing staff and the family members.

After conducting the interviews, the information gathered were transcribed and analyzed. The analysis was guided by the following questions: (1) How are social needs understood? (2) What position does social needs and social care have within a nursing home context? (3) What position does social needs and social care have among family members? The focus of the first question was to capture how family members understand, organize and make use of the concept of social needs in relation to a nursing home context. The second question explored what properties, functions and positions social needs have in a nursing home context and among the nursing staff. The last question explored how family members experience their position regarding social care for their elder. The analysis followed a process compatible with the theoretical perspective, meaning that I looked for tendencies in the ways family members spoke about social needs and social care, and how they positioned them both within the nursing home context, but also regarding caregiver roles. Things I deemed to be of particular interest was annotated, and is presented in the result section.

# Ethical clearance and further implications

As social needs and social care are concepts that might impose sensitive information, this thesis got its ethical clearance in connection to the sub study on KOMP, which was assessed and approved by The Norwegian Centre for Research Data (NSD, project 406771, see attachment 3). It was emphasized that sensitive interview questions, for instance on health challenges, were to be avoided. This is because the topic of interest was not in the sites of sensitive health challenges, but in the broader experiences on social needs and quality of life. Furthermore, the interview process was audio recorded after family members' consent, and the audio files were stored in TSD to ensure anonymity. Family members were also informed about their anonymity and their right to withhold responses or abandon the interview. In this thesis, all names, places and other topics of identity are anonymized, by leaving these identifications out and by the use of pseudonyms.

The interviews were conducted in Norwegian. All statements included in the thesis were translated by the author. Since the translation is constructed and defined by me as a researcher, certain characteristics of the conversations can be left out. For example, since the thesis bases its analysis on the spoken statements, the analysis will leave out the family members' emotional expressions and hesitations. Moreover, cultural meaning of phrases might also be left out, as language and culture are highly intertwined. For this reason, when reflecting and discussion the results, I studied the Norwegian versions of the quotations to minimize the impact of the translation (Freeman, 2009).

The thesis theoretical perspective, as inspired by micro-interactionist traditions, make the researcher's personal experiences, prejudices and assumptions a part of the data-gathering process, as the understanding of social needs is a product of social interaction. My background from health- and social psychology influences the ways the social concepts are attended to. For instance, what I discover and find interesting in the data. Additionally, how I constructed the semi-structured interviews sat guidelines for the interview (Hale, Treharne & Kitas, 2007). Own assumptions prior to the research were that humans' social, psychological and physiological aspects are intertwined concepts, mutually influencing one another. Therefore, I expected to find a broad understanding of social needs, related to psychological and physiological aspects. Furthermore, that these three concepts would be prioritized differently within the nursing home, expecting a down prioritizing of psychosocial needs in favor of physiological, or medical, needs. As a co-constructer of the data, I was interested in how family members make sense of the world around them in order to create frames to

understand social needs and social care, including me as a part of the social worlds that influence them.

The thesis treats family members statements as expressions of their experiences, as their attempt to make sense of the world as it is right now. The data is therefore dependent on the social context from which the family members derive their experiences. One contextual factor was the KOMP-project. As the family members already were enrolled in a project focusing on KOMP, their experience with KOMP and the process of its installation in the nursing home might have influenced the ways in which they talked about social needs and social care. However, this influence was probably more profound in the follow-up interviews, where the conversation was directed towards their experience on KOMP, and family members often tended to conversations of the devices positive and negative sides. However, I found it easy to guide the interview towards relevant topics for the research question, regarding social needs and social care.

Another contextual influence was the corona pandemic. The corona pandemic influenced both the methodic procedure and its results. As the nursing staff experienced demanding working conditions, and the elders being particularly vulnerable to the virus, it was easier engaging in contact with family members. Thus, resulting in the family members perspective as building blocks for this study. The interviews were done in a time embossed with social isolation and media coverage of loneliness (Støren, Rønning and Gram, 2020; Oslo kommune, 2021; Ertzeid, 2020; Nettavisen, 2020). This can potentially benefit the study, as the family members might have been more aware of situations, aspects or ideas regarding social needs that they might have overlooked or taken for granted if the social circumstances were different. Their awareness on sociality as caused by social isolation might have encouraged a more profound conversation on social needs. It might have also facilitated openness in the interview setting, as social isolation was more present in peoples' daily lives during the corona pandemic, and therefore a less shame related topic.

The corona pandemic also made it difficult to do interviews in person, which resulted in a bigger notion of video interviews and telephone interviews. This might have had an impact on the interpersonal aspects in the interview setting. By comparing the one interview in person, with the video or telephone interviews regarding depthless of information, I would argue that the corona pandemic did not have a significant impact of the quality of the interviews. The interview done in person did last for a longer period of time, but didn't show any clear advantage regarding richness of information or the overall comfort of the interview

situation. During the video call, one family member asked for renewed confirmation on their anonymity. This could be a sign of insecurity in the study's confidentiality, but after confirmation on the anonymity, the family member gave detailed information on their experiences and personal opinions. I would also describe the situation as nonthreatening, as the family members were ensured of their anonymity, talking to a younger student. This again, might also have been beneficial regarding openness and richness of information.

# 4. Results

The results presented took base in the ones I found to be most appropriate to answer the research question: **How are social needs and social care understood within a nursing home context?** The analysis was guided by the following questions: (1) How are social needs understood? (2) What position does social needs and social care have within a nursing home context? (3) What positions does social needs and social care have among family members? The way social needs and social care are understood and positioned in the family members' accounts, say something about what the concept of social needs is within a nursing home context, and how social care is embedded in the nursing home practice.

#### How are social needs understood?

When studying the ways family members reflected on their elders' needs, I found a tendency to mention physical needs as related to social needs. As this will be exemplified in the following sections, it caused for reflections on how social needs and physical needs relates to one another, and what this implies for the understanding of caregiving roles in relation to social care in the nursing home. Moreover, how social care within the nursing home relate to the understanding of social needs as linked to individuality. The term *social needs* were openly used in the interview setting, leaving it up to the family members to direct the topics of conversation based on what they deemed to be relevant. For this reason, the results reflect family members' perception of their elders' social needs, and their thoughts on how social needs are met, or should be met, within a nursing home context. This information was then used to reflect upon what social needs are within the nursing home context.

### Social needs as general needs

One way to explore how family members understand the concept of social needs, was to ask them directly about what they find to be the nursing home residents' social needs. The interview questions were phrased as *Could you tell me what you perceive to be the nursing home residents' social needs?* or *Do you have any thoughts on what a nursing home resident has for social needs?* An example of a response to this interview question was from a daughter, with her mother in the nursing home:

That is of course to have contact with her children and her family. [...] Otherwise, social needs are...That in the ward, there could have been some likeminded for her to have contact with. I have previously been in the ward and seen some of them. Those in the wheel cheers, and the heavy patients [de tunge pasientene]. But to have someone to talk to, as long as they can talk. Or that when they can't talk on their own, someone talks to them. That's important. And then preferably by the nursing staff. It's not something new, that this would be nice. But it is just...how much time they have.

With this response, we see social needs as related to having someone to socially interact with. It can seem natural that social needs are related to opportunities to be social. In this example, the family member perceives these needs as something that can be cared for by many different social actors. Both family members, the nursing staff, and other nursing home residents.

Another way to capture how social needs are understood, is to look at what specific measures family members recognize as social care. During the interview, family members were asked *Do the nursing staff usually do something to care for [the nursing home resident'] social needs?* Or phrased as *What is it that the nursing staff does in order to ensure that [the nursing home resident] is well socially?* One daughter who has her mother in the nursing home responded:

No other than getting her out of bed. They have managed to get her in the shower and things like that. She has been dreading it, as she cannot shower on her own. But she can't manage that anymore. But she trusts them... So, if they do anything else for her...I am not sure.

In this example, we see social care as related to helping nursing home residents to get out of bed, and helping them shower. The family member perceives these measures to improve her mother's social life, which may seem strange. Helping the nursing home resident to get out of bed and shower are related to the nursing home residents' physical needs. This can indicate an unclear distinction, or a strong relation, between social needs and physical needs. In this response, there also seems to be an underline of the nursing staff helping the nursing home resident out of a process of dread, based on their relation built on trust. Being showered by others can foster issues of dignity and independence. Therefore, this response suggests social needs as related to feelings of dignity, as well as feelings of safety when being in trustful hands. Another response to this question was from another daughter with a mom in the nursing home:

I think...They have to bring her to the meals. I don't think they do anything besides bringing her to the meals. I have mentioned that it would be nice to visit the café and that, but I think that has happened only once [...]. Also, there has been someone who has been inside and talked, and she finds that very nice, when they have taken the time to sit with her. There was someone who had been sitting with her on her bed and talked, and told her about her children and her family, and where they came from. And my mom thought that was very nice.

We also see a tendency here, for social needs to be related to meals, as a physiological need. However, there is an emphasis on how the staff brings the resident to meal time, perceived as social care. The place for the meal time is a place where the residents are socially gathered. Therefore, bringing the resident to meal time is related to bringing the resident to an environment for social engagement. The response also suggests social needs as related to what is nice, which in this case is either visiting a café or having personal conversations with the nursing staff. Social care seems to include the nursing staff to take time to personally engage in conversations with the nursing home resident.

One thing to take from this is how the concept of social needs and social care seem to have a broad range of applications. A result that might seem expected, but not less important, is how social needs and social care are related to the opportunity to be social. Family members view both themselves, other nursing home residents and the nursing staff as caring

for elders' social needs, indicating that the need for someone to talk to is seen in the light of a general human need for socializing.

Furthermore, the results indicate social care as related to attendance to the elders' physical needs, such as helping them shower, getting out of bed or bringing them to mealtime. Similar to the need for socializing, these physical needs are also general in nature. All people need to shower and eat, and as many elder's experience deteriorating health, it is considered normal for elders to need help managing the needs. Even though getting help from others include a social aspect, it is not an obvious social need. It is closely linked to a need for physical attendance or supervision which does not guarantee an opportunity for social engagement. Yet, caring activities that are provided to help the resident cover these general needs are considered social by the family members. Moreover, these caring activities seem related to the maintenance of residents' dignity, as well as promoting feelings of comfort and safety. These can all be argued to be related to residents' wellbeing. Caring activities promoting these feelings are also considered social. This way of understanding social needs is linked to the nursing home residents' emotional experiences. Even though the emotional experience is a product of social interactions, it is an individual experience that, likewise the physical needs, does not guarantee an opportunity for social engagement.

Why are these caring activities considered social? One reason might be that being showered and getting out of bed can prompt more positive social feedback from others, compared to not being showered or staying in bed too long. In other words, it can be seen as ways of enhancing the chances for social engagement. The same can be argued for feelings of dignity and safety. Having dignity involves being seen and treated as a human being in need of positive interactions. Moreover, feeling safe can be seen as a necessity in order to socially engage. The satisfaction of basic human needs, such as being showered, getting out of bed and feeling well, leads to the possibility of fulfillment of higher, perhaps more personal, needs. It can therefore be argued that social needs are seen as a higher type of need. A need fulfilled after the more basic human needs are fulfilled.

The take on this is that social needs within a nursing home context are perceived as more than social engagement according to family members. It is a broad concept related to sociology, physiology and wellbeing. The concept of social needs takes base in humans general need for socially engaging, managing physical needs and feeling well. Things mentioned as related to social needs don't have much in common, apart from being caregiver tasks without a clear health professional or medical profile. Social needs therefore seem like a

broad category involving tasks within the nursing home that does not include healthcare or medical care.

#### Social needs as personal needs

Throughout the interviews, social needs were spoken about in relation to specific things family members perceive to be important for their elder. For instance, during the interview, family members would often mention specific things that the resident likes or desires. This was things such as chocolate, cakes, history books, television, newspapers and beer. The topic of conversation was related to family members' wanting to ensure availability of these things for their elder. As a part of a response to the interview question *What do you understand to be the nursing home residents' social needs?* One family member answered "It is me who bought the TV, and hung it on the wall. Since there is not much room there. But... to have chocolate available, or fruit." Another family member stated this about his dad in the nursing home: "He gets really happy when we bring him beer, so that he can take a glass of beer. Not that it is any big deal, but he enjoys it a lot when he gets to drink a glass of beer".

These examples suggest an understanding of social needs as related to specific things that brings the elder feelings of enjoyment and happiness. Fruits and chocolates are tied to personal preferences. Social needs are therefore related to the fulfillment of personal preferences in order to foster experiences of enjoyment and happiness. The link between social needs and beer might seem farfetched or odd. It assigns a social component to the enjoyment of a beer or a fruit. What is it that makes family members pursue this relation?

The relation between social needs and beer might find its explanation in the way family members tend to refer to who their elder were prior to moving to the nursing home. For example, when asked *Do [the nursing home resident] have the opportunity to do the things he/she enjoys in the nursing home?* one daughter said the following about her mother: "She enjoys reading the newspaper. And she is a bit sad about that now, because now she can't do it." Here we see the problematizing of the resident no longer being able to do the thing she enjoys. This response suggests a link between enjoyment and the elders' state prior to the nursing home, and therefore a disconnect between enjoyment, and who the elder is now. Another family member responded this about his mom:

There used to be a difference between the weekdays and the weekends. She used to think the weekdays were boring. But now it is not much of a difference. So, now she thinks the weekends are boring too. And it isn't much going on during the week either.

Here we see an example of a tendency to mention how things were prior to the move to the nursing home. The life in the nursing home is also considered more boring than the life before moving to the nursing home. When asked what is it that he/she enjoys doing now? A family member responded "Now? Nothing. She used to knit a lot. Solve crosswords. She read. She does none of these things anymore, she doesn't have the energy for it." Again, there is a tendency to connect enjoyment to what the elder used to do prior to the nursing home. This suggests that family members perceive the nursing home as a place in which enjoyment, or opportunities for enjoyment, wither away.

The statements also suggest issues regarding the link between enjoyment and the elders' present state. Reasons for this given in the family members' statements, is that the resident no longer can do the same things, or don't have the energy to do it. In other words, that the opportunities for enjoyment are changing as the elders' health deteriorates. Another reason for a disconnect between enjoyment and the elders' present state could be that what the elder enjoy is changing in itself. We see examples on this from the interviews. One daughter stated this regarding engaging her mother:

We have tried with knitting...We have asked if she wants an e-book to listen to, since she says she don't have the energy to read. But she is not in a place where she wants that either. And we don't want to push. She still has her own free will. She must be allowed to decide for herself.

In this response, the mother is not in a place to want new adjusted forms for enjoyment. This suggests that the mother's state has changed. We also see a connection between enjoyment and pleasure, and the need for dignity and independence. One son stated this about his father:

He has nothing he is interested in. I have asked if he wants to go visit the house he used to live in as a child, but "it's not that important" and "I can't leave my wife". I have asked if he wants to go on a car ride, but "no…it's not that important". He is

reduced to a state where being able to sleep, get some good food, a glass of beer now and then... And, he wants a glass of cognac for Christmas.

The father's interests have changed as he is reduced to another state than his previous state. This indicates that it is not just the father's physiological health that has changed, but also who he was as an individual, what he used to enjoy and what he was interested in. This can potentially complicate social care measures, as it can be hard to grasp the connection, or disconnection, between what the elder used to enjoy, and what they enjoy now.

The statements from family members also show a distinction between the nursing home resident prior to, and past the move to the nursing home. One family member stated that "I think it is important that when you come to a nursing home, you should continue to be the person you have always been". Here, it seems as though the nursing home itself has a task of preserving the elders' individuality. Implying a task to enable the elders to keep doing what they have always enjoyed doing.

For several family members, the process of their elder's health deteriorating was described as their elder being "reduced". For example, in sentences such as "After she came to [Name of the nursing home], she has gotten very reduced", or stated by another family member: "She was actually quite outgoing. She did a lot of things. She is a very active person who has gotten very reduced. Gotten very passive."

The word *reduced* indicates a state where there is less of something. Perhaps, less of who the elder used to be, or what they used to do. Being outgoing and active are personal traits. These statements can therefore be argued to indicate a linkage between deteriorating health and loss of the elders' identity. With this in mind, it can be argued that family members perceive social care to include environmental adjustments in ways that is protective of their elders' individuality. We see an understanding of social needs that includes maintaining the elders' individuality, and not just their social engagement. In a response to an interview question regarding what a nursing home resident has of social needs, one family member, who has both his parents in the nursing home, responded:

For my mother...To have a friend she can talk to would be valuable. Maybe an arranged visitation friend could've covered that. But she wants someone on her own age with similar interests. If she had that on a daily base, I am sure her cognitive functions would have been maintained to a larger degree. [...] For my father I think

the ship has sailed. If he had gotten someone to play cards with a little earlier [...] I think it could have helped him too.

In this response we see a link made between social needs and the maintenance of the residents' cognitive functions. This suggests that social care is understood to be to care for the residents' cognitive health. Furthermore, that the family member is not mainly worried about the withering of their elder physically, but the withering of the elder as a person. The relation between social needs and beer might not be so farfetched after all. The argumentation above makes ensuring availability of what the elder personally enjoy, a matter of maintaining the elders' individuality.

Knowledge of what the elders enjoy are often attributed to the family members. There are several statements from the interviews that indicate this. For instance, one family members said "We call once in a while. I ask if there are something they need, my father enjoys a glass a beer, so then I will ask if he has any beer left." Here, the family member is the one who actively calls the nursing home in order to ensure availability of beer. In another example, one partner of a nursing home resident informs the nursing staff on what her husband prefers: "I have made a list. Where there is a kind of instruction manual on [name of nursing home resident], about what he likes and stuff like that." Here, the family member took initiative herself to ensure that the things her partner enjoys were available to him in the nursing home. One take on this is therefore that it is the family members who most often pursue to buy chocolate, beer and other things that the resident enjoys.

When social needs are understood as related to enjoyment and happiness, it seems to be closer linked to the family members caregiver role. One reason could be that they perceive themselves to have more knowledge of the elders' individual preferences. Moreover, it can be difficult for the nursing staff to acquire this knowledge as with the time limit and often changing shifts. It can therefore be argued that seeing social needs as related to individuality makes it difficult for the nursing staff to ensure extensive social care. This can cause for a need for family members to contribute in processes of social care in the nursing home context. As well as a need for collaboration between the family members and the nursing staff to ensure extensive social care. Furthermore, the perspective on enjoyment and happiness as related to the maintenance of a withering personhood can serve to re-evaluation of the importance of providing such services. It's not just a nice thing, but something to help maintain residents' individuality.

As the results suggest, social needs are more than social engagement and social interactions. Based on the argumentation in the sections above, social needs within a nursing home context are what everybody needs. Social needs are help when you are physically reduced, such as help with showering and being brought to mealtime. It is also about building trust to the nursing staff and feeling safe. It is also more than what everybody needs. It's what the individual needs, to persist. Social needs are related to the personal experiences of enjoyment and happiness. Things often related to a state of wellbeing, something beyond fulfillment of general human needs such as good health.

The separation between social needs as general and person specific was exemplified during the interview. When one family member was asked *Could you tell me what you perceive to be the nursing home residents' social needs?* She asked back "Do you mean in general or based on my own mother?". This indicates two different ways of talking about social needs, which again can entail different forms of social care. Social needs as what everybody needs, leads to general approaches for social care. For example, arranged joint activities. However, social needs as related to individuality would lead to a person specific approach based on the residents' individual preferences.

# What position does social needs and social care have within a nursing home context?

During the interviews, I found a tendency to arrange different measures in the nursing home within a hierarchy based on their importance. Such a hierarchy could be due to limited resources in the nursing home, such as time, that causes for the need to prioritize between different measures. The focus was to investigate social needs and social cares' position within the nursing home context. Furthermore, the position of social needs when social needs are seen as related to nursing home residents' individuality.

### Healthcare prioritized before social care

There are several occasions in the interviews where the family members used the Norwegian phrase "det er ikke så farlig", which can be translated to *it's not a big deal* or *it's not that important*. One family member used this phrase in relation to what her partner in the nursing home was wearing: "One day he had the neighbor's shirt on. It wasn't his. But it's not really a big deal, but…". Also, about the slow process of getting her partners' TV to function:

"also about the TV. It took four weeks because the janitor was ill. But it wasn't a big deal. But now it works." The family member is here downplaying the importance of proper clothing and the functioning of the TV. This means that they know, and want to signal that they know, that some things are more important. As discussed in the previous section, the concept of social needs is used in a broad sense by the family members, relating to feelings of comfort, safety, enjoyment and happiness. When the argumentation from the previous sections is placed in the light of this downplaying, having proper clothing and having a TV fits within the category of social care. This is because wearing one's own clothes can be seen as a way to express residents' individuality or preserve dignity. Furthermore, watching TV can be seen as an action for enjoyment. Therefore, it can be argued that it is social care practices who are being downplayed by the family members, but in favor of what? One partner of a nursing home resident stated:

We managed to get an arrangement where he showered every day, since showering is just as quick as a body wash. I thought that he maybe smelled a bit the last time. But it doesn't affect his health, as long as they are joyful when they do it. But he was probably showered more rarely.

Here, we see that showering often isn't arranged highly on importance, but rather second to the nursing home resident's health and that the staff is joyful. In this statement, measures within the nursing home are arranged by importance relating to how much they affect the residents' health, suggesting health as a main priority. According to this statement, showering the resident is not ranked as high importance unless it is a matter of health.

In the previous sections I mentioned that family members often talked about availability of specific things that bring the nursing home resident joy and happiness, such as beer or chocolate. Or related to the last section, TV-watching. It would therefore seem contradictive if family members deem availability of these things to not be of importance. Taking a closer look at the communicative premises between the nursing staff and the family members can help shed light on why family members perceive health as a priority, downgrading social care.

Examples suggests that family members don't get information form the nursing home about availability of things such as chocolate, beer etc. One family member stated: "I have asked if there is something she misses, and if there are something we should fix. Because, I

don't get that information, about what she misses. But when I ask, I get clear answers." Another example shows little information in regards to what the elder is doing socially: "I don't know what my mom is joining in on, and what she is not. Except for those times I ask". For family members having to ask in order to get this information says something about what the nursing staff prioritizes of information, and how family members caregiver role is positioned. It is not given that family members should have information about what the elder is doing socially, and it is not a given that consummation that causes enjoyment or happiness are ensured.

Furthermore, it suggests that family members lack insight as to what is going on in within the nursing home. For instance, the nursing home was described as a "black bag" or a "closed off institution" by two different family members. The family member does give an explanation for the black bag metaphor. It is because "you get to visit, but then in a specific meeting room environment", and also that because of corona "you never get to see [the nursing home resident] in the environment". This makes family members highly dependent on information from the nursing staff in order to know how their elder is doing socially within the nursing home.

What do the nursing staff inform family members about? According to the family members, they receive phone calls for the nursing home often in relation to practical or health specific matters:

There was a time when my mom always wanted cake. So, it was a lot of cake. So, her blood sugar would go up. And then they called to say it would be nice if not all of us brought cake all the time.

Or, from another family member: "They call if he has fallen and stuff like that. I am a bit unsure what I am supposed to do with that information. He hasn't died or hurt himself. It can be nice to know but...". These examples indicates that, according to family members, the nursing staff calls are often based in health-related matters. Blood sugar and keeping the elder from hurting themselves are both matters of importance for maintaining the elder's physiological health.

The examples can also reflect a potential conflict between the priority of healthcare versus social care. Firstly, the phone calls telling family members to stop bringing cake can contradict their wish to ensure the elders' enjoyment. Secondly, there is an inconsistency with the information given by the nursing staff and the information that the family member seems

to want. In the second example presented above, the family member is not sure what to do with the information that her partner had fallen. This can indicate that the family members don't find the information appealing to her caregiver role, as her partner falling is something the nursing staff should attend to. The partner falling can be seen as related to the resident's health, as the family member makes an association between the falling with death and hurting oneself.

The way family members don't get information related to chocolate and beer, but still ask for it, can indicate a longing for this information. Yet, what they get information about is health related. These communicative premises can therefore give the family members an impression that social needs as related to chocolate and beer are not prioritized by the nursing staff.

There are some examples from the interviews where family members describe receiving letters from the nursing home about social activities [during Christmas]. According to their description, this information is in letterform. If the nursing home informs family members about social activities through letters, it is a one-way communication. It signals that family members are not expected to respond or to play a part in the creation of these arrangements. And with that letter, the nursing home are not interested in the family members opinions or ideas, but simply to inform them.

These findings suggests that family members don't expect the nursing staff to inform them about what the elder is doing socially, but that they do expect information the elder's health. This indicates that information regarding health has higher priority in the nursing home context. Furthermore, family members are also showing that they know that this is the order of things by downplaying activities for social care. It also seems that the nursing staff contact the family members to inform them on what needs to be done, for example to buy less cake, and not to inform the family members in itself. The communicative process seems to be influenced by a focus on efficiency and task orientation. The lack of information about how the elder is doing socially can mean that collaboration of social care between the nursing staff and family members are not incorporated as a main working task within the nursing home context.

#### Person specific care as an ideal, and not an expectation

A political goal is to ensure extensive care for nursing home residents, including that all nursing homes who wants it, receive training, support and guidance on how to put in place activities and good experiences for the individual nursing home resident (Meld St. 15, 2017-2018, s.61). Family members seems to share the same ideal about extensive care within the nursing home. One family member stated that "During the Christmas time they have a nice programme. So, then I hope, and think, that they get my mother to engage" and "The staff on the specific ward has to, kind of, gather them, which they do. Talk to them. Spend time with them. I think that's important." This suggests that the nursing staff is wanted as a contributor to the elder's social wellbeing by family members.

There are examples in the interview where the nursing staff does things for the nursing home resident that goes beyond ensuring health. For instance, one son of a nursing home resident talked about a situation where his daughter had created a show for his mother in the nursing home, on her birthday. He explained that, after that séance the nurses had "Taken photos of the séance and printed it, and hung it up on her room.", which he then characterized as a "very nice gesture". A *gesture* can be defined as an act to be given a deeper meaning (Store norske leksikon, 2021). Indicating that family members perceive this form of person specific care as unexpected, an act of deeper meaning separated from normal everyday activities. In the interviews, there are also cases where the nursing staff is referred to as being or doing good. One family member stated: "The nurses, they are good, they recognize me on my voice.", and continued: "there are many there who knows his name and knows who he is when he comes walking. There are many wards, but they are probably good at learning names. In the reception as well."The family member perceive the nursing staff to be good when learning or remembering names, indicating that this is not an expectation associated with their caregiver role.

Taking photos for the nursing home resident, or remembering names, can be argued to involve more person specific attention than showering and bringing the nursing home resident to the work out room. These person specific actions are framed by family members as something extra, or as an exception from normal day happenings. It is suggested that family members do want the nursing staff to engage with the elders at a personal level. As it is not expected, the family members get happy or satisfied when these gestures occur. A personal relation between the nursing staff and the nursing home resident is not expected by the family members. This indicates a distance between the staff and the nursing home resident, which might be due to structural arrangements such as nursing staff changing shifts or having limited time.

These findings also indicate that social care, as related to person specific measures as done by the nursing staff, is devalued compared to healthcare. Even if family members do wish for a personal engagement between the staff and the residents, it is accepted by the family members as an ideal and not something to be expected. Healthcare is therefore legitimized as a priority within the nursing home context.

The acceptance of the low priority of social care, as compared to health care, should not be taken as evidence of the low standing of social needs among family members. On the contrary, there seemed to be an almost insatiable amount of wishes on the family members' part, for improvements in the nursing home with regards to social needs. Often as a wish for more contact and information from the nursing staff regarding what the residents do, want and need. For example, one son said that "It would be nice that if when you bring something extra, you would get a message saying that now they are enjoying this and that." As argued in the previous section, person specific care is not something the family members expect. Therefore, it can be argued that family members settle for healthcare as a priority above social care, even when wishing for a bigger priority of social care.

The argument that family members settle for healthcare as priority, can be backed up by looking at how family members seem to not state their dissatisfaction to the nursing staff. One family member said that "I will not argue if there are many residents in line to get a haircut. Then that's just how it is". Meanwhile, another family member said this regarding what her mother does in the nursing home: "I have found out that I don't call to ask about those things. I wait for it to be more, so I can do a summed-up call about more things at once".

It seems to be a reluctance to state their dissatisfaction, for which there can be several reasons. One reason could be that family members feel less suited to infer or state something about the nursing home context as they have reduced insight on what is going on within the nursing home due to the corona restriction. Additionally, their reduced insight can cause for them to be in an inferior position where they don't feel like they can demand changes within the nursing home.

Another reason for not stating their dissatisfaction could be out of respect for the nursing staff, who they might view as strangers that sometimes go out of their way to do nice gestures for their elder. Phrases that indicate this is "the poor people who work there" or "it is not that easy for the nursing staff". This was mentioned in relation to how one nursing home resident had anxiety for things to be stolen, which the family member understood to cause

complications for the nursing staff. Phrases like this has also been mentioned in relation to the newer corona restrictions in the nursing homes where the residents had to stay in their own rooms. Based on the telling from one family member, this caused for the nursing staff to be rough towards the residents, especially those with dementia, trying to keep them from wandering the halls as a way to protect their health. This can therefore indicate that family members have respect or sympathy with the nursing staff, and not complaining can therefore be a part of not wanting to complicate things for them.

In addition to having respect for the nursing staff, and lack of knowledge and supervision on what is going on in the nursing home, it can also be because of an impression that it doesn't work. For example, one family members said "you can always wish for things, but it's not always things that can be done" and "it's about how the entire system is", which can reflect that their opinions are only small in comparison to the whole system arranged to care for their elders. One reason is stated directly: «I haven't asked about it now, because it is the corona that makes things difficult", or "but we don't nag about it. We think it is the Corona that limits them a lot." In this sentence, stating dissatisfaction is seen as nagging. This suggests that family members perceive themselves to withhold less power over the processes happening within the nursing home.

Not stating their dissatisfactions can also be a decision made in order to prevent being perceived as bothersome. One family member stated that she would feel "very controlling" if she were to ask for things from the nursing staff. When the family member is in a situation to feel controlling, it indicates that they do not have the main control over the situation, and that they perceive control as not theirs to take. Thus, it can be argued that it is the nursing staff or the nursing home who sits with the control. One family member also gave an explanation for why family members might feel bothersome when stating their dissatisfaction: "It is clear that, it is much more difficult for them to deal with the family members. [...] It is a lot of work. It demands more resources". Here, for the nursing staff to deal with family members is perceived as making their job more difficult. It takes up resources, such as for example time or energy.

Whatever reason, family members reluctance to state their dissatisfaction can stem from an acceptance of the priority of health within the nursing home. They talk about the difficulties nursing staff has regarding priority of resources. Yet, they don't suggest a redistribution of the existing resources in favor of more extensive social care. A health

perspective within the nursing home context has therefore an unquestioned authority over social care.

# What position does social needs and social care have among the family members?

If the family members were accepting but unhappy about the low priority of social demands and social care in the nursing home, what did they think about their own care work and responsibilities? My informants indicated that they worked hard to organize and conduct visits, but that they were unable to visit enough. Apart from that, they were very unclear about what the nursing staff expected of them as caretakers, and tended to view themselves as passive players in the order of care. What family members do regarding social needs, and how they relate to their caregiver role, is used to further elaborate what social needs and social care is within a nursing home context.

#### Visitation as work

Throughout the interviews, visitations were a prominent topic. The quantity of the visitations was often mentioned, even repeated. Examples are "I am there once a week or "we have been together one or two times a week". The quantity is also stated for the callings "after she came to the nursing home, we have called every day", or stated as something not being done anymore: "I don't talk to my mom every day on the phone anymore, I used to". The mentioning of visitations in the interview setting means that family members perceive it to be of relevance or importance in relation to social care. I would therefore argue that visiting often enough is something family members strive for, and something they perceive as an important part of their caregiver role.

In the cases where the family members have siblings, the visitation process was described as a rolling task between them. When asked about if she could tell a little bit about his parents in the nursing home, he started his answer with "I want to say our relationship is really nice. We have kind of had contact the entire way. And I want to say that, we are three siblings who distribute the visits." This suggests that visitation is something to be distributed between the siblings. In relation to caring for the elders in the period before the decision to move into nursing homes, the caregiving tasks was also said to be *distributed* between the siblings:

We tried, my brother first. [...] So, did me and my sister distribute visits so we were there twice during a week each. So, in four out of seven days one of us visited and prepared food and saved it so they could eat them the other days.

Here, the siblings cooperate to ensure their parents proper food and care. Visitation seems to be perceived as working tasks that have to be distributed between siblings to make sure the caregiving adds up to an ideal. The brother's contribution was to move in to the parents' home. The son explained that the reason for this was because "he hadn't taken any of the previous sessions", as he lived further away. The visitations are here described as sessions, which can be argued to give associations to a tiresome process that has a clear beginning, and a clear ending. The siblings team up to get the sessions done, to take the load off each other. The word distribute also makes visitation seem like a working task. There are several components, in this case three siblings, that has to cooperate and create a visiting combination in order for the task to be fulfilled. This might not be strange. Afterall, there is a long tradition within the social sciences of perceiving caring as a form of work, as care work (Vabø, 2018). With this in mind, family members way of phrasing suggests visitation to be their perceived caregiver task.

There are many reasons as to why visitations are distributed between siblings. Reasons could be due to the corona pandemic's influence, that restricts the possibility for families to visit. In this case, distribution ensures that all siblings get to see their parents. However, the son did refer to distribution of visits prior to the corona pandemic, and also prior to the parents move to the nursing home. Another reason could be to ensure that the parents get regular visits. This entails an understanding of visits as important for the elders' health or wellbeing, or also likely the sibling's health and wellbeing as they find it pleasant to visit their parents. Visitations can also be distributed to ensure that that the siblings all contribute to caring for the elder so no siblings are left with all responsibility. This seems plausible as the siblings have children, jobs and other things filling their days, leaving often visitation unattainable to be provided by one sibling alone. It can therefore be seen as a combination of the siblings wanting to ensure that their parents get visits, as well as allowing them to combine caring for their parents with other things going on in their lives.

In one case, the partner to the nursing home resident were still alive, and the children hadn't visited yet. In that case, the nursing home resident also had friends visiting. The family

member said that «One American friend managed to book a visit. He usually visits when he is here. And he has brought things such as a collage he had made with photos from their trips to England". This suggests that family members and friends want to ensure the elder regular visitation as an important part of their caregiver role.

There is also a tendency among many family members to give an explanation as to why someone hasn't visited or called enough. One example is from the partner of a nursing home resident: "[The children] hasn't visited him for the time being. But he has only been there for six weeks". Another family member talked about not calling her mom everyday anymore, and explained this by staying that her mom gets confused and stressed when she calls. It was also explained in relation to her sister calling more often: ""But my sister and I are trying to unite us a little on the callings. She calls because she lives in [place far away], and do not visit during corona. So, she calls the most, and I visit." Another family member, a daughter of the nursing home resident, had a similar strategy with her sister: "I may have called every other day. Or every three days... and maybe my sister a little less often. But she may have stayed with her a little longer when she visited." The following of an explanation suggests that not visiting requires a justification. Thus, it is not accepted as a norm to not want, or not be bothered, to visit.

The presented results suggests that family members perceive visitation as an important care work assigned to their role. That they work towards coordination of visits can indicate that family members know that care work is expected of them. Furthermore, the need to justify or explain when someone isn't visiting can be based in feelings of shame as they don't visit enough. Thus, not living up to what is expected of them.

#### Working together with the nursing staff to ensure elders social needs, or?

Newer political aims are to facilitate collaboration between nursing home residents' family members and the public health services to improve care for elders needs (Jenhaug, 2018; Prop. 1 S, 2020-2021; Meld St. 15, 2017-2018, s.10). One take on this is that both caregiver roles should be involved in processes that care for the nursing home residents' social needs, in order to ensure extensive care. Since this thesis has a base in family members' perspective, it is interesting to take a closer look at which expectations they perceive the nursing home to have to their caregiver role. In the interview, family members were asked directly: *Do the nursing home have any expectations to you regarding the elders' social needs?* To this interview question, most family members responded with confusion.

Responses were "Hm...no? I don't think so. No other than that I meet up and tell them when I'm going to visit", "No. And yes, it's strange!" and "I do nothing!". Their responses, as well as their body language, showed that this was clearly an odd question. This can indicate a disconnect in the collaboration for social care. The family members perceive the nursing home to not expect anything from them. Which can mean that family members perceive their involvement in social care as a choice, and not as a part of an extensive collaboration with the nursing home. Some family members find it strange as they experience minimal expectations to their caregiver role. A partner of one nursing home resident stated:

No one has ever told me that "he has to few shirts" or that "He should've had a hat". Because, one time he didn't have a hat. And I felt really bad. So, I ran down there with a hat one day, and just that day he was about to go out on a trip.

In this particular case, the partner would have wanted to know about the lack of a hat, so that her partner wouldn't get cold during the wintertime. This suggests a lack of communication between the nursing staff and the family member. Moreover, that expectations to the family members are unclear or not communicated by the nursing staff. In this particular case, the family members, but likely also the staff, would be better poised to provide for the residents' needs if they communicated better. It is also interesting that in an interview question about social needs, the informant referred to a situation where lack of a physical need, chances of getting cold, was the focus. This again, can reflect how the concept of social needs is highly intertwined with health, and that collaborating on social care also includes collaborating on matters of health.

Looking beyond the oddness of the interview question, some family members perceived the nursing home to have some sort of expectations to them. One family member said "Well, they always say that it is nice when we visit. So, I think they would have thought it was sad and weird if we didn't keep in touch. I think so." This suggests an expectation to the family members based on habits. The nursing staff are used to the family members visiting, and therefore expect it. However, there can be argued to be a distinction between expectations as tasks assigned to their caregiver role, and expectations in the form of not being surprised when the family members show up. Expectations to family members as assigned to their caregiver role seems either nonexistent, or not a part of family members'

perception of their role. To the interview question on expectations, one family member responded:

There a no [expectations] spoken... but there are many things that no one else does [...] So the nursing home doesn't say that I need to do them, but the nursing home doesn't do them, so it is a none spoken expectation that somebody else has to do it.

What is it that no one else does, regarding caring for the elders' social needs? When talking about social needs, family members often fall back into a topic of them bringing the elder things like chocolate, beer, history books or cakes. Which has previously been argued to be things that family members perceive to be less of a priority for nursing staff. With these arguments at hand, if the family members view these tasks as important, yet chose not to do them, it will probably not be done by someone else. As the family members don't talk about any direct expectations from the nursing home, these responsibility tasks for social needs are something they place on themselves in relation to how important they perceive the action to be. If they see bringing the elder chocolate and beer to be important for their elders' social wellbeing, and no one else does this, the responsibility become theirs. Thus, self-proclaimed and based on their own idea of what the elder needs from them. More communication with the staff regarding social needs might therefor be beneficial for helping family members provide social care for their elders. Both to make their care work easier in practical ways, as well as giving family members insight as to what the elders needs from them.

# 5. Discussion

This thesis explored how social needs and social care are understood within a nursing home context. Based on interviews with family members of nursing home residents, I found that social needs are understood in both general and personal terms. Moreover, that family members downplay social care within the nursing home context. Suggesting that healthcare is prioritized within the nursing home context. I also found that social needs as personal is not expected from the nursing staff, but associated with family members' caregiver role. Furthermore, that social needs as personal is something the family members deem important as a way to maintain the elders' personhood. In the following I will discuss the results' meaning and implications.

# Social needs as both general and personal

The results showed two prominent ways of understanding social needs. One was more general in nature, meaning that the understanding was based on what everybody needs. This were things such as social contact, feelings of safety and comfort, and help with showering and getting out of bed when physically reduced. The other way to refer to social needs took base in person specific desires. For example, ensuring enjoyment of things the resident likes to eat or read, as parts of maintaining the residents' personhood. The two ways of understanding seem to be from different edges of a continuum of general versus specific. However, social care in practice is not nearly so black and white. It often exists somewhere along the lines between general and specific. For example, when taking into account personal preferences when fulfilling general needs. This can be where family members' notions of elders' dignity and comfort get its relevance, as personal experiences. For the family members, social needs were about maintaining the elders' personhood, and not just their bodies regarding physiological health. Meaning that social care can't be separated from caring for the wholeness of a residents' personhood, their individuality and personality. This argues for extensive social care to include fulfillment of general needs, as well as a more individualized approach.

# Implications for social care: Who and How

When social needs are understood in different terms, it can cause for confusion in who is to care for social needs, as well as how extensive social care is to be achieved. Social needs as general are cared for by those present for the nursing home resident, which often are the nursing staff. Yet, family members can also fulfill general needs. For example, when they help the elder get dressed, or follow them in the hallways of the nursing home. Meanwhile, social needs as person specific is best cared for by those who know the residents' personal needs the best. Which can cause for conflict regarding who knows the elders needs the best. The family members lack insight into how the elder is acting when they aren't around. Therefore, the nursing staff might feel more informed to make decisions about the elder's social desires. Meanwhile, family members often have a more personal relationship to the elder, as well as a longer history of knowledge about the elder that they can take into account. It can therefore be that family members perceive themselves as best suited to care for the elders' social needs.

What if the elder is no longer who they used to be? Through the interviews, I found that family members tend to talk about the elders' social needs in relation to the elders' prior state, before the move to the nursing home. Often with a base in what the elder used to enjoy. These results suggest that family members relate social care to maintaining the elders' personhood. In other words, they have a desire for maintaining the elders' personhood by facilitating enjoyment and happiness. Thus, it can be argued that the desire reflects what the family members want for their elders, and are not based on the need's family members have experienced to be stated by the elders themselves. This indicates that social care, as based in person specific desires, need to look at who the elder is now, and not who they are supposed to be in the eyes of family members. As the nursing staff might know more about who the elder is now, instead of who they are supposed to be, it can cause for conflicts as to who are best suited to care for the elders' social needs. Which can argue for a need for collaboration between the caregiver roles.

Changes in nursing home resident's personhood are well documented in the body of research. For instance, Riedl, Mantovan and Them (2013) argued in their article that nursing home residents "develop a new identity close to their previous identity by maintaining autonomy and mobility with a clear focus on the future." (p.1). It has also been argued that maintenance of nursing home resident's identity can be beneficial for resident's wellbeing and quality of life (Cohen-Mansfield, Golander & Arnheim, 2000), as well as sustain memory, facilitate care and reinforce the elders' self-value (Vèzina, Robichaud, Voyer & Pelletier, 2011). Arguing that family members' desire to maintain the elders' personhood might have something to it. Yet, in many cases, there has already been a change in the elders' identity, which I would argue shouldn't be ignored. Therefore, this implies that approaches for social care needs to take into account both who the elder is now, as well as who they used to be.

This continues the argumentation from the introduction, which stated the need for improvement in collaboration between the nursing staff and the family members in order to ensure extensive social care. Studies suggest that moving to a nursing home can induce loneliness among the elder population (Hagan et al, 2014; Slettebø, 2008). It is therefore a need to improve social care within the nursing home context. As the results indicate two prominent ways of talking about, and understanding, the concept of social needs, it argues for a declared strategy for social care including an understanding of social needs as both general and personal. As social needs as a personal need takes into account the maintenance of

personhood, there is a need for more research on how information on the elder's present desires can be captured.

# The nursing home as an extensive care facility

As mentioned in the introduction, a political aim is to ensure extensive social care for elders, concerning both elders' physical and mental health, as well as promote social security and prohibit social problems (Halvorsen and Stjernø, 2008; Meld. St. 15, 2017-2018; Helseog omsorgstjenesteloven, 2011). Despite an ambitious definition, The World Health Organization made it clear that health is not just about physiology and psychology -the social aspect is also involved, as one of three health domains. (World Health Organization, n.d, para. 1). Nursing homes are a health caring facility, but how do they navigate and prioritize between the different domains of health?

The association between social networks, and both the elders' subjective wellbeing and physiological health, is well established in the literature. Here, social networks often relate to the elder's network of family and friends. Meanwhile, subjective wellbeing can be understood as a positive orientation toward life expressed in measures such as positive affect, morale, feelings of happiness and life satisfaction (Litwin and Stoeckel, 2013, p. 1265; Cornwell and Waite, 2009; Fiori, Antonucci and Cortina, 2006; Hagan et al. 2014). Therefore, both the ideal of physiological health and the ideal of wellbeing, seem relevant in relation to social care. Therefore, the nursing home should attain both ideals in order to ensure extensive social care. Do they?

Results suggest a positioning of social care as inferior to healthcare within the nursing home context. This was found when family members downplayed aspects of social care corresponding with social needs as both personal and general needs. Additionally, it was found when personalized social care by the nursing staff was seen as unexpected gestures. Information regarding the elders' social state was also found to be unprioritized by the nursing staff, in favor of information regarding physiological needs.

As results suggests that social needs are highly intertwined with maintaining the person, it indicates that maintenance of the person is related to health. Creating a triangular relation, where maintenance of the person can promote health, and good health facilitates social engagement (Cornwell and Waite, 2009; Fiori, Antonucci and Cortina, 2006). The priority of healthcare, combined with lack of resources to give more than the minimum, makes the nursing home into a place that favors maintenance of the body, and not the person.

This priority of healthcare can be a contributor to making family members withhold their concerns or dissatisfaction with how the elder is doing socially, and further limit their contribution as a resource for their elders.

The prioritizing reflects a norm of health as primary insurance of physiological wellbeing, prior to social and psychological wellbeing. The nursing home is after all, for the most part, staffed by health care professionals, such as physiotherapists and nurses, and not social workers. Maybe this reflects a lacking perspective in order to ensure extensive social care? According to the family members, the social engagement between the nursing staff and the nursing home residents seem to fall short due to a health focus. As social needs can be both general and personal in nature, does this leave social care dependent on both arranged social activities and unarranged social interactions?

Several things indicate a positive affect from personal engagements between nursing staff and nursing home residents. One study saw that for the nursing staff to acquired strategies to maintain the nursing home residents' identity, such as evoke elements related to their nationality, marital status or place of birth, results in a more personal relationship between the nursing staff and the resident, which again made it easier for the staff to care for the president's personal hygiene, meals and bedtime (Vézina et al., 2011). Another study has also argued that nursing home residents cope with identity changes by sharing own stories with the nursing staff and other residents (Riedl et Al., 2013). These studies therefore suggests that a more personal relationship between the nursing home resident and the nursing staff can be beneficial.

One way to ensure extensive care of elders' social needs could be for the nursing staff to interact with the residents at a personal level, enhancing the chance for personal relations to develop. This would demand for the nursing staff to have enough time and resources to sit down with the residents and get to know them, as well as for the nursing staff to have a personal dedication to personally interact with the residents. It could also be that a focus on giving the nursing staff more time to personally interact with the residents could enhance their personal dedication to care for their social needs. As shown in the result section, one family member stated: "The staff on the specific ward has to, kind of, gather them, which they do. Talk to them. Spend time with them. I think that's important". Here, the family member suggests for the nursing staff to have more time to talk and interact with the elders as something that could improve the elder's social situation

According to political documents, caring for elders' social needs is a political goal. However, this goal alone, does not provide resources to meet the social needs. One political document seem to be influenced by a general understanding of social needs, stating that "all elders should be offered at least one hour of activity every day based on their own interests and wishes "(Meld St. 15, 2017-2018, p.7). Alongside, ensuring extensive care by stating that "elderly people should have the opportunity to live at home for as long as possible, and receive support to cope with everyday life, despite illness and disability." (Meld St. 15, 2017-2018, p.21). Here, it is a focus of maintaining the elders' individuality, which accommodates the family members focus on person specific desires. However, the measures take into account a general approach compared to the family members, who talk about specifics such as ensuring the elder beer and chocolate, or other things they enjoy.

When these particulars are left out of the political documents it can cause for confusion as to how to strategically handle this form of social care, which I would argue is perceived as important by the family members. Furthermore, a priority of social care attending to the more general social needs. This can affect the extensiveness of social care.

Leaving out the understanding of social needs as personal, can potentially diminish their fulfillment. For instance, prevent the elder from reaching a higher degree of social wellbeing, consisting of enjoyment and happiness. Moreover, as studies suggest health benefits regarding maintenance of the elders' identity, leaving out personal social needs from political strategies can further limit reaching a goal of extensive social care (Cohen-Mansfield et al, 2000; Vèzina et al. 2011). Insights from the nursing staffs' perspective would be a great contribution in this discussion, providing information on how personal social needs can or is included in the nursing home measures, as well as to why family members perceive the social care in the nursing home as inferior to healthcare.

# Family members as contributors of social care

The results suggest that family members perceive visitation as an important part of their caring responsibilities. They coordinate visits in order to ensure their elder social contact with loved ones, and give an explanation when visitation don't occur. Furthermore, family members also bring the resident things they enjoy, such as chocolate or beer. This has previously been discussed as a person specific form of social care, one that entails giving the elder things they have enjoyed all their lives as a part of maintaining their personhood. However, the results suggest that family members perceive the nursing home to not have any

clear expectations to their caregiver role. Not in terms of visitations, nor regarding bringing things for the elder to enjoy. This can indicate that they view what they do for their elders' social needs to be a personal choice, a responsibility they take themselves. However, the way siblings coordinate visitations, alongside explaining when one sibling seems to visit more rarely, can indicate that social norms for caregiving is at play. For instance, that not visiting due to not wanting to, is not an acceptable excuse, and that family members should visit the nursing home resident if they have the chance.

In the results, it is shown how family members are the ones reaching out to the nursing home regarding availability of things the resident enjoys, and that if they don't reach out themselves, they don't get that information. This shows a down prioritizing by the nursing home of social needs as personal needs. If family members deem things such as beer and cake to be important for the residents' social wellbeing, they have to care for this themselves. This can show a segregation between the caregiver roles, where the family members care for the personal social needs, meanwhile the nursing home cares for the general social needs. As the family members are the ones who lack insight as to what goes on in the nursing home, both due to the corona pandemic or as they are not with the elder at all times, social needs as personal needs seem to have a lower standing in the nursing home. This is also shown in the ways information flow regarding social needs and social care are deprioritized by the nursing staff. The segregation in social care creates the need for closer cooperation between the nursing staff and the family members. Or the need for social needs as personal and general to be unified into one declared strategy for social care.

Social care as caring for the residents' personal needs, or personhood, seems to fall short as a part of the nursing staffs' caregiver role. This is shown in the ways family members describe it as good or nice when the nursing staff manages to remember a resident's name, suggesting a low expectation to the nursing staffs' person specific care. Caring for social needs as personal needs, might require personal dedication by the nursing staff. This is because they would have to take the time to get to know the resident, in ways that make them aware of what they need to enjoy themselves or to feel happy. This would mean that the nursing staff have to be open and generous towards the elder in a way that affects them personally. This can be the reason as to why family members don't expect the nursing staff to care for the residents' personal desires, but take on these caregiver task themselves. As personal dedication is a personal matter, it can cause for difficulties distributing responsibility for social needs as personal needs. Furthermore, it makes social needs as personal needs into

something that family members can't expect from the nursing staff, and something the nursing staff can't expect from the family members. This causes for unclarity as to how these needs should be looked after, and by whom.

As shown in the introduction, family members inclusion can better the psychosocial environment for the residents, as well as improve their health and the nursing home service (Nakrem & Hynne, 2017; Rognstad, Sagbakken & Nåden, 2014). As the results indicate, family members are not utilized as a resource as much as they could. Through the interviews, I found a lack of conversation about the elders' social needs. Moreover, family members felt confusion as to what is expected of them regarding social care. Additionally, the family members lacked insight as to what the elder is doing socially by the nursing staff. They also didn't state their dissatisfaction or questioned the authority of healthcare prior to social care. This suggests a need for the family members and the nursing staff to talk more directly about social needs and social care, pulling their efforts into a strategy for extensive social care.

# 6. Concluding remarks and future research

This thesis has explored how social needs and social care are understood within a nursing home context. I found that social needs are a broader concept than first anticipated. It has both a general and a personal dimension, which should be included in measures for social care in order to ensure its extensiveness. I also found that social care is downplayed in favor of health care. This argued for a broader view of health as related to social- and psychological wellbeing, in order for the nursing home to be an extensive care facility. Moreover, the understanding of social needs as personal, and as maintaining the elders' individuality, seem to fall short as a part of the nursing staff's caregiver role. There is therefore a need to develop strategies for how to include the understanding of social needs as personal within social care measures, as well as enhancing collaboration between the nursing staff and the family members to enhance the potential benefits of family members as a resource. Further research is needed on how to include a broader perspective of social need within the nursing home practice, as well as studies on its potential benefits for elders' social wellbeing.

The results are based on the perspective of six family members. Interviewing more family members would provide beneficial insights. Moreover, the results shed light on family members' experiences, that enriches the knowledge on what social needs is from the family members perspective. The results don't explore family members' opinions regarding social needs. Further research is needed on both family members', nursing staffs' and nursing home

residents' opinions on how to care for social needs. Moreover, the thesis lacks insight from the nursing homes and the nursing home residents. Future research should examine how social needs, and the division of social care with the family, are understood by the nursing staff. Moreover, test different collaboration models where family members who wish to do so, can influence the content of the social care that the nursing home resident receives. This can shed light on both what kind of potential that exists to improve social care practices within the nursing home, and on the resources, and organizational and social carriers, that prevent the utilization of this potential.

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# Attachment 1: Interview guide

# A)Forholdet mellom deg og beboer

# 1) Hvem er beboeren er for deg?

a. Hvordan ville du beskrevet ditt/evnt. andres forhold til beboeren? (Familie, venn, nabo)

# 2) Kan du fortelle meg litt om beboeren?

- a. Hva er det beboeren liker å bruke tiden sin på?
  - i. Hvordan var dette før beboeren kom på sykehjem?
  - ii. Har beboeren mulighet til å gjøre det h\*n liker på sykehjem?
- b. Har du noen tanker om hva som gjør at beboeren har det bra sosialt?
- c. Når flyttet beboeren på sykehjem?
- d. Hvordan var prosessen fra hjem til sykehjem, kan du si noe om det?

# 3) Hvordan ville du beskrevet forholdet mellom deg og beboeren før

# koronapandemien?

- a. Hva pleide dere å gjøre noe sammen?
- b. Når/Hvordan foregikk dette?

# 4) Hvordan har koronapandemien endret kontakten mellom dere?

- a. Er det noe dere gjør mer eller mindre av?
- b. Kan du fortelle meg litt om hvordan dere kommuniserer da dere ikke møtes?
- c. Opplever du at kommunikasjonen mellom dere har blitt dårligere eller bedre under koronapandemien?
- d. Hvordan tror du kontakten mellom dere vil bli nå fremover?

# B) Ditt og beboers forhold til personale på sykehjemmet

# 1. Jeg er også interessert i forholdet mellom beboeren og personalet. Hvordan ville du beskrevet dette forholdet?

- a. Hva pleier personalet å gjøre for at beboeren har det bedre sosialt?
  - i. Har du noen tanker om hvorfor de gjør det på denne måten?
  - ii. Er det noe du tenker burde vært annerledes? Hva? Hvorfor?
- b. Skiller dette seg fra hva du pleier å gjøre med beboer?
  - i. Er det bra eller dårlig at dette er forskjellig? På hvilken måte?
- c. Hvordan var forholdet mellom personalet og beboer før koronapandemien?

- i. Når forholdet mellom personalet og beboer endres, hvordan påvirker dette deg?
- ii. Påvirker det forholdet mellom deg og beboer på noen måte? Hvordan?

# 2. Hvordan er ditt forhold til personalet ved sykehjemmet?

- a. Hvordan vil du beskrive kontakten du har med personalet?
  - i. Kan du si noe om hvordan samtalen foregår?
- b. På hvilken måte har koronapandemien påvirket forholdet mellom deg og sykehjemmet?
- c. Hvordan snakker dere om beboerens sosiale behov?
  - i. Hva snakker dere om?
- d. Har du mulighet til å si ifra om du vil at noe skal gjøres mer eller mindre av?
  - i. Hvordan kunne du gått fram for å si ifra?
  - ii. Hvorfor tror du det er slik?
  - iii. Har du selv forsøkt å si ifra om noe?
    - 1. ja: hvordan ble dette møtt av sykehjemmet?
    - 2. nei: hvorfor ikke?
- e. Er det noe annet du vil nevne om ditt forhold til personale eller sykehjemmet?

# C) Dine tanker om beboerens sosiale behov og ivaretakelsen av disse

# 1. Kan du fortelle litt om hva du tenker er beboerens sosiale behov?

- a. Hva er det beboeren trenger?
- b. Hvem kan sørge for at beboeren får det h\*n trenger?

# 2. Hvordan opplever du at de sosiale behovene til beboeren blir tatt vare på under pandemien?

- a. Er det noe det burde gjøres mer eller mindre av?
- b. Hvordan har pandemien påvirket deg og ditt liv?
- c. Hvordan er det å være pårørende under pandemien?

# 3. Har du noen tanker om hva som kan gjøre slik at beboerens får det bedre sosialt?

- a. Hva forventer du av sykehjem/personalet i denne forbindelsen?
- b. Hvilke forventninger har du til andre i familien?
- c. Hvilke forventninger har du til deg selv?

# 4. Kan du si litt om hvordan du opplever din rolle som pårørende til en sykehjemsbeboer?

- a. Hva forventer andre i familien av deg?
- b. Hvilke forventninger har beboer til deg?
- c. Hva forventer sykehjemmet av deg?
  - i. Har du og personale snakket om dette?
- d. Hva tenker du om forventningene til deg?
  - i. Burde dette vært annerledes? På hvilken måte?

# 5. Du deltar jo i KOMP-prosjektet. Hvilken informasjon har du fått kom KOMP som produkt?

- a. Ja: På hvilken måte fikk du denne informasjonen?
- b. Nei: hvorfor tror du det ble slik?
- c. Har du noen tanker om/forventninger til prosjektet?
- d. Har du noen tanker om hvordan KOMP kan bidra til at beboeren får det bedre sosialt?

Jeg vil gjerne prate mer med deg om dette etter at du har fått KOMP. Hadde du vært åpen for et kortere oppfølgingsintervju?

# D)Oppfølgingsintervju om KOMP

- 1. Kan du fortelle meg litt om oppstarts-prosessen med å bruke KOMP?
  - a. Hvordan foregikk denne omstillingen?
  - b. Var det noen utfordringer med å starte å bruke KOMP?
  - c. Hvor lenge har du og beboer brukt KOMP nå?
- 2. Jeg vet du har svart på dette i spørreundersøkelsen, men jeg må spørre likevel.

# Hvordan bruker dere KOMP nå?

- a. Hva bruker dere den til, og hvor ofte ca.?
- 3. Hvordan har forholdet mellom deg og beboer endret seg etter dere tok i bruk KOMP?
  - a. Har du som pårørende hatt noen fordeler av KOMP? Hvilke?
  - b. Har beboeren hatt noen fordeler av KOMP?
- 4. Hva opplever du at er forventet av deg i utprøvingen av KOMP? Av sykehjemmet, fra beboeren, andre?
- 5. Vil du si at KOMP har hjulpet med å innfri beboerens sosiale behov?
  - a. Har KOMP gjort det enklere å innfri beboerens sosiale behov?
  - b. Er det noen andre måter å innfri beboerens sosiale behov på, som fungerer bedre enn KOMP?

# Attachment 2: Information letter

Hei!

Jeg er en masterstudent ved Institutt for sosialfag, OsloMet, som har tilknytting til forskningsprosjektet «Enkel og trygg pårørendekontakt» (KOMP-prosjektet). Jeg tar kontakt med deg fordi du deltar i dette prosjektet, og har samtykket til å kontaktes for et forskningsintervju. Jeg skal skrive en masteroppgave om hvordan sykehjemsbeboernes sosiale behov blir forsøkt ivaretatt under pandemien, med strenge besøksrestriksjoner og andre smitteverntiltak som gjør fysiske besøk vanskelig. Jeg er spesielt interessert i hvem som jobber for å ivareta disse behovene, hvordan dette skjer, og hvordan helsepersonell og pårørende kommuniserer i forbindelse med de sosiale behovene. Jeg lurer også på om KOMP kan være et nyttig verktøy i forbindelse med dette. Derfor ønsker jeg å komme i kontakt med pårørende til sykehjemsbeboere med tilknytning til KOMP-prosjektet, da de sitter på unik erfaring om utfordringene knyttet til å ivareta sosiale behov i disse tider, og hvordan KOMP eventuelt kan bidra.

Deltagelse vil innebære et intervju med ca. 45-60 minutters varighet. Intervjuet kan gjennomføres fysisk eller over telefon/video, det er opp til deg (fysisk intervju tilpasses de aktuelle smittevernrådene). Alle opplysninger om deg vil behandles anonymt, og det vil ikke være mulig å gjenkjenne deg når resultatene publiseres. Ved å dele dine erfaringer bidrar du ikke bare til ny og relevant kunnskap om ivaretakelse av sykehjemsbeboere, men også hvordan teknologien kan være med på dette. Din deltagelse ville derfor blitt satt stor pris på. Jeg lurer derfor på om du ønsker å stille til et intervju?

Hilsen Tonje Margrethe Gustavsen, MA-student ved Institutt for sosialfag, OsloMet.

# Attachment 3: NSD: Reporting form/Meldeskjema

E/11/2021

Meldeskjema for behandling av personopplysninger

# NORSK SENTER FOR FORSKNINGSDATA

## Meldeskjema 406771

#### Sist oppdatert

24.11.2020

#### Hvilke personopplysninger skal du behandle?

- · Navn (også ved signatur/samtykke)
- · Lydopptak av personer
- · Bakgrunnsopplysninger som vil kunne identifisere en person

#### Type opplysninger

#### Du har svart ja til at du skal behandle bakgrunnsopplysninger, beskriv hvilke

Vi skal behandle bakgrunnsopplysninger knyttet til demografiske/ sosioøkonomiske forhold som ofte har vist seg å være relevante variabler for å forstå samfunnsmessige forhold, herunder ensomhet blant eldre og betingelsene for ensomhetsbekjempelse på institusjon.

De fleste av opplysningene vi etterspør gjelder beboerne, men noen gjelder også ansatte ved sykehjemmene, og de pårørende. Når det gjelder beboerne, ønsker vi å behandle opplysninger om respondentenes alder, landbakgrunn, kjønn, utdanningtype, samt deres oppfatning av egen livssituasjon og deres erfaringer med kommunikasjonsteknologien KOMP. Når det gjelder pårørende til beoberne, ønsker vi å behandle opplysninger om alder, kjønn, landbakgrunn og utdanningstype. Når det gjelder ansatte begrenser vi oss til alder og kjønn.

#### Skal du behandle særlige kategorier personopplysninger eller personopplysninger om straffedommer eller lovovertredelser?

Helseopplysninger

## Prosjektinformasjon

### Prosjekttittel

Enkel og trygg pårørendekontakt

# Prosjektbeskrivelse

Som ledd i et innovasjonsprosjekt i samarbeid med Sykehjemsetaten i Oslo og teknologiutvikler No Isolation skal OsloMet undersøke tilpasningen og bruken av kommunikasjonsløsningen KOMP til bruk på institusjon. KOMP er en skjerm laget for eldre med lite digital kompetanse, for å redusere ensomhet og bedre kontakten med pårørende. OsloMet skal forske på prosjektet, for å

- Undersøke effektene av bruk av KOMP for eldre på institusjon for å redusere sosial isolasjon og ensomhet

https://meldeskiema.nsd.no/eksport/5f33bcef-4318-47fa-90c3-74911cc9adee

#### 5/11/202

#### Meldeskjema for behandling av personopplysninger

 Etablere kunnskap om implementasjon av velferdsteknologi i stor skala, og om betingelsene for offentligprivat samarbeid i den forbindelse.

Prosjektet er støttet av Norges forskningsråd, basert på utlysningen "COVID-19 hasteutlysning: Innovasjonsprosjekt med privat-offentlig samarbeid (BIA-X)". Da det er et "Covid-prosjekt" hvor snarlig oppstart er ønsket av alle parter, ber vi om å prioriteres i saksbehandlingskøen dersom dette er mulig og forsvarlig.

#### Begrunn behovet for å behandle personopplysningene

Det skal samles inn personopplysninger fra ansatte, ledere og beboere ved 17 sykehjem, samt fra beboernes pårørende. Det er flere grunner til at det er nødvendig å samle inn personopplysningene i denne undersøkelsen.

Den første handler om ensomhet og ensomhetsbekjempelse. Det er grunn til å tro at ensomhet, og også betingelsene for å bekjempe ensomhet ved bruk av kommunikasjonsteknologi, varierer med forhold som de vi undersøker her. Behandling av de angitte personopplysningene vil dermed hjelpe oss å si noe mer sikkert om målte variasjoner i opplevd ensomhet skyldes innovasjonen eller andre forhold ved sykehjemsbeboerne og disses materielle og sosiale omstendigheter.

Den neste handler om innovasjon i offentlig sektor. For å sikre solid kunnskap om hva som fungerer og ikke fungerer rundt implementeringen av KOMP-teknologien i de aktuelle sykehjemmene, er det viktig å også vite noe om de som jobber ved sykehjemmene. Dessuten, gitt at formålet med innovasjonen er å sikre bedre kontakt mellom beboer og pårørende, så er det også viktig å lære av og om de pårørende. Det kan hende lokal suksess ved enkelte sykehjem kan forklares av organisatoriske forhold ved sykehjemmet, eller til faktorer knyttet til selve implementeringsprosessen. Men disse forholdene kan igjen avhenge av om det f.eks. er unge eller gamle ansatte eller pårørende som er initiativtakere.

#### Ekstern finansiering

· Norges forskningsråd (NFR)

#### Type prosjekt

Forskerprosjekt

## Behandlingsansvar

# Behandlingsansvarlig institusjon

OsloMet - storbyuniversitetet / Fakultet for samfunnsvitenskap / Institutt for sosialfag

## Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Erik Børve Rasmussen, fossan@oslomet.no, tlf: 92210882

Skal behandlingsansvaret deles med andre institusjoner (felles behandlingsansvarlige)?

Nei

#### Utvalg 1

Beskriv utvalget

# https://meldeskiema.nsd.no/eksport/5f33bcef-4318-47fa-90c3-74911cc9adee

Ansatte og ledere ved sykehjemmene som deltar i prosjektet.

#### Rekruttering eller trekking av utvalget

Sykehjemsetaten, ved velferdsteknologi-koordinator Anna-Stina Ferner, rekrutterer sykehjem som skal delta i innovasjonsprosjektet. De oppretter også kontakt mellom ledere ved sykehjemmene og ØsloMet.

Sykehjemsetaten rekrutterer en lokal prosjektleder, enten ved hjelp av sykehjemslederen eller via andre formelle kanaler. I tillegg til å være ansvarlig for å velge ut beboere som får prøve KOMP, vil de lokale prosjektlederne være nøkkelinformanter for OsloMet. Alt dette vil kandidater til rollen som lokal prosjektleder være informert om før de beslutter å delta.

Øvrige ansatte ved de aktuelle sykehjemmene vil informeres skriftlig om prosjektet, gjennom sykehjemmets informasjonskanaler. Det er da ansatte som jobber med de av beboere som deltar i prosjektet og som derfor skal få eller har mottatt en KOMP, som vil bli rekruttert som informanter. Leder eller lokal prosjektleder setter OsloMet i kontakt med de aktuelle ansatte, som deretter blir bedt om informert samtykke til å delta i prosjektet. Deltakelse innebærer at man besvarer en spørreundersøkelse i tre omganger, og at man godtar å kontaktes for et evt. forskningsintervju (enkeltvis eller i grupper). Også ledere ved de deltagende sykehjemmene vil bli spurt om de er villig til å kontaktes for et evt. forskningsintervju.

#### Alder

20 - 67

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Nei

#### Personopplysninger for utvalg 1

- Navn (også ved signatur/samtykke)
- Lydopptak av personer
- · Bakgrunnsopplysninger som vil kunne identifisere en person

#### Hvordan samler du inn data fra utvalg 1?

## Elektronisk spørreskjema

## Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

# Personlig intervju

## Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

## Gruppeintervju

## Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

# Informasjon for utvalg 1

#### Informerer du utvalget om behandlingen av opplysningene?

https://meldeskjema.nsd.no/eksport/5f33bcef-4318-47fa-90c3-74911cc9adee

Ja

#### Hyordan?

Skriftlig informasjon (papir eller elektronisk)

#### Utvalg 2

#### Beskriv utvalget

Sykehjemsbeboere som deltar i prosjektet

#### Rekruttering eller trekking av utvalget

Innovasjonsprosjektet handler om å få implementert KOMP-løsningen hos beboere på sykehjem. Det er derfor et mål å innhente data om beboere som bruker KOMP, og deres brukererfaringer.

Et viktig ledd i rekrutteringen av beboere blir prosessen knyttet til tildelingen av KOMP. I samråd med utvikler No Isolation og OsloMet, vil etaten utvikle enkle tildelingskriterier for å delta i prosjektet og prøve KOMP. Ett av kriteriene vil være samtykke til å delta i prosjektet (altså at man ved å prøve KOMP også går med på å dele erfaringene med forsøket). Med deltagelse menes her at man svarer på en spørreundersøkelse i tre omganger, om livssituasjonen, med fokus på sosial omgang og livskvalitet. Vi vil på den måten kun rekruttere de beboerne som skal få KOMP i sin boenhet. (Deltakende beboere vil informeres om at de når som helst kan gi fra seg KOMP-enheten og trekke seg fra studien). I tillegg kan det bli aktuelt å holde korte personlige intervju.

I rekrutteringen av beboere vil vi måtte vurdere fra situasjon til situasjon hva som må til for å sikre samtykke. Vi forventer at noen av de aktuelle beboerne vil mangle eller ha redusert samtykkekompetanse, og vil støtte oss til de ansattes informasjon og råd knyttet til dette. I noen slike tilfeller vil det trolig være nødvendig at pårørende gir samtykke på beboernes vegne.

#### Alder

70 - 105

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Ja

## Begrunn hvorfor det er nødvendig å inkludere voksne som ikke kan samtykke.

Prosjektet handler konkret om å bedre livssituasjonen til eldre personer som bor på sykehjem, ved å innføre et kommunikasjonsmiddel som skal redusere ensomhet og bedre kommunikasjonen med både pårørende og ansatte. Vi er derfor avhengig av å innhente informasjon også om erfaringene til eldre pleietrengende på sykehjem, for å kunne si noe om hvorvidt tiltaket bidrar til å redusere ensomhet og til å styrke kommunikasjonen. Spesielt siden ensomhet er en opplevd følelse mer enn en objektivt verifiserbar tilstand. Da kronisk ensomhet har en dokumentert og sterkt negativ effekt på folks livskvalitet, mener vi derfor det er viktig og riktig å inkludere sykehjemsbeboerne i undersøkelsen.

## Personopplysninger for utvalg 2

- Navn (også ved signatur/samtykke)
- · Lydopptak av personer
- Bakgrunnsopplysninger som vil kunne identifisere en person
- Helseopplysninger

https://meldeskjema.nsd.no/eksport/5f33bcef-4318-47fa-90c3-74911cc9adee

Meldeskjema for behandling av personopplysninger

Hvordan samler du inn data fra utvalg 2?

Elektronisk spørreskjema

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ia

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ja

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Informasjon for utvalg 2

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriftlig informasjon (papir eller elektronisk)

Mottar personer som ikke kan samtykke tilpasset informasjon om prosjektet?

Ja

Utvalg 3

Beskriv utvalget

Pårørende til sykehjemsbeboere som deltar i prosjektet

Rekruttering eller trekking av utvalget

https://meldeskjema.nsd.no/eksport/5f33bcef-4318-47fa-90c3-74911cc9adee

5/11/2021

Meldeskjema for behandling av personopplysninge

Siden et hovedsiktemål med undersøkelsen er å bedre kommunikasjonen mellom beboer, ansatt og pårørende, er det viktig å få med data om pårørende i undersøkelsen. Det vil også fungere som et tildelingskriterium, at beboerne som får KOMP faktisk har familie/pårørende. (Prosjektet har ikke kapasitet til å administrere alternative kontaktordninger, som "besøksvenn"-ordningen til Røde Kors).

Pårørende vil rekrutteres via den lokale prosjektlederen. Prosjektet er lagt opp slik at ansatte ved sykehjemmet (enten den lokale prosjektlederen selv, eller ansatte denne har lært opp) lærer opp en eller et mindretall pårørende i å bruke KOMP (hvordan man sender beskjeder og bilder, hvordan man ringer opp, hva beboeren selv kan gjøre, og hvordan man får knyttet andre pårørende til KOMP-løsningen). Pårørende som er i kontakt med ansatte i denne sammenhengen vil bli spurt om tillatelse til å bli kontaktet av forskere. Ved tillatelse får vi kontaktinformasjon av de ansatte på sykehjemmet, og sender epost eller ringer, for å informere om prosjektet og be om samtykke. Dersom kontakt etableres over telefon, vil informasjon om prosjektet sendes skriftlig som eletronisk eller analog post, før den pårørende gir samtykke til å delta. Deltagelse innebærer i denne sammenhengen å svare på en elektronisk spørreundersøkelse i tre omganger, og å godta å kontaktes for et eventuelt intervju.

#### Alder

18 - 80

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Nei

#### Personopplysninger for utvalg 3

- Navn (også ved signatur/samtykke)
- Lydopptak av personer
- · Bakgrunnsopplysninger som vil kunne identifisere en person

Hvordan samler du inn data fra utvalg 3?

#### Elektronisk spørreskjema

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

# Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Informasjon for utvalg 3

Informerer du utvalget om behandlingen av opplysningene?

Ja

## Hvordan?

Skriftlig informasjon (papir eller elektronisk)

### Tredjepersoner

https://meldeskjema.nsd.no/eksport/5f33bcef-4318-47fa-90c3-74911cc9adee

#### Skal du behandle personopplysninger om tredjepersoner?

Ja

#### Beskriv tredjepersoner

Vi kommer til å behandle personopplysninger om beboerne som er avgitt fra ansatte ved sykehjemmet (det er kun snakk om beboere som deltar i prosjektet og prøver KOMP i den forbindelse, og som vi har fått samtykke fra eller på vegne av). Noen slike opplysninger vil være nødvendig for å kunne svare adekvat på forskningsspørsmålene til prosjektet. Vi vil instruere de ansatte til å begrense seg til å opplysninger om beboere som er relevant for å forstå beboernes bruke av KOMP og effektene av bruken. Særlig gjelder dette forhold som knytter seg direkte eller indirekte til ensomhet og psykisk ned- og oppstemthet, som er sentrale i dette prosjektet. Vi vil ikke be om personopplysninger om andre beboere. Vi kan stille spørsmål om enheten samlet sett, men ikke om enkeltpersoner. Vi kommer ikke til å samle inn eller behandle personopplysninger om andre beboere.

All den tid prosjektet undersøker kontakten mellom beboere og deres pårørende, er det uungåelig slik at beboere vil omtale sine pårørende, og at pårørende vil omtale de aktuelle beboerne. Derfor kommer vi også til å behandle personopplysninger om beboere som er avgitt av pårørende, og personopplysninger om pårørende som er avgitt av beboere.

#### Typer opplysninger om tredjepersoner

- · Navn (også ved signatur/samtykke)
- · Bakgrunnsopplysninger som vil kunne identifisere en person
- Helseopplysninger

#### Hvilke utvalg avgir opplysninger om tredjepersoner?

- · Utvalg 2: Sykehjemsbeboere som deltar i prosjektet
- Utvalg 3: Pårørende til sykehjemsbeboere som deltar i prosjektet
- Utvalg 1: Ansatte og ledere ved sykehjemmene som deltar i prosjektet.

#### Samtykker tredjepersoner til behandlingen av opplysningene?

Ja

# Mottar tredjepersoner informasjon om behandlingen av opplysningene?

Ja

# Dokumentasjon

#### Hvordan dokumenteres samtykkene?

- · Elektronisk (e-post, e-skjema, digital signatur)
- · Manuelt (papir)

## Hvordan kan samtykket trekkes tilbake?

Vi oppgir en epostadresse og en postadresse i informasjonsskrivet, som deltakerne kan bruke for å ta kontakt og informere om at samtykket trekkes tilbake. Adressene er knyttet til undertegnede.

## Hvordan kan de registrerte få innsyn, rettet eller slettet opplysninger om seg selv?

https://meldeskjema.nsd.no/eksport/5f33bcef-4318-47fa-90c3-74911cc9adee

5/11/2021

Meldeskjema for behandling av personopplysninger

Ved å benytte de overnevnte adressene kan deltakere i prosjektet ta kontakt med forskerne og be om innsyn, korrigering og sletting. Dette opplyses det om i informasjonsskriv til deltakerne.

#### Totalt antall registrerte i prosjektet

100-999

#### Tillatelser

## Skal du innhente følgende godkjenninger eller tillatelser for prosjektet?

· Annen godkjenning

# Annen godkjenning

Det innhentes tillatelse fra sykehjemsetaten og fra det enkelte sykehjem til å gjennomføre studien (se informasjon om rekruttering).

#### Behandling

## Hvor behandles opplysningene?

- · Maskinvare tilhørende behandlingsansvarlig institusjon
- · Mobile enheter tilhørende behandlingsansvarlig institusjon
- · Ekstern tjeneste eller nettverk (databehandler)

## Hvem behandler/har tilgang til opplysningene?

- Prosjektansvarlig
- Student (studentprosjekt)
- Interne medarbeidere
- Eksterne medarbeidere/samarbeidspartnere innenfor EU/EØS
- Databehandler

# Hvilken databehandler har tilgang til opplysningene?

Det er surveyprogrammet "UiO nettskjema", og OsloMet har en databehandleravtale med dem allerede.

# Tilgjengeliggjøres opplysningene utenfor EU/EØS til en tredjestat eller internasjonal organisasjon?

Nei

# Sikkerhet

### Oppbevares personopplysningene atskilt fra øvrige data (koblingsnøkkel)?

Ja

# Hvilke tekniske og fysiske tiltak sikrer personopplysningene?

· Opplysningene anonymiseres fortløpende

https://meldeskjema.nsd.no/eksport/5f33bcef-4318-47fa-90c3-74911cc9adee

#### 5/11/2021

Meldeskjema for behandling av personopplysninger

- Adgangsbegrensning
- · Opplysningene krypteres under forsendelse
- Endringslogg
- Flerfaktorautentisering
- · opplysningene krypteres under lagring

#### Varighet

#### Prosjektperiode

01.09.2020 - 31.12.2024

#### Skal data med personopplysninger oppbevares utover prosjektperioden?

Nei, data vil bli oppbevart uten personopplysninger (anonymisering)

#### Hvilke anonymiseringstiltak vil bli foretatt?

- Koblingsnøkkelen slettes
- · Personidentifiserbare opplysninger fjernes, omskrives eller grovkategoriseres
- · Lyd- eller bildeopptak slettes

Vil de registrerte kunne identifiseres (direkte eller indirekte) i oppgave/avhandling/øvrige publikasjoner fra prosjektet?

Noi

# Tilleggsopplysninger

KOMMENTAR TIL DEN VEDLAGTE PROSJEKTBESKRIVELSEN: Den vedlagte prosjektbeskrivelsen er søknaden som ble sendt til Forskningsrådet, og som rådet valgte å støtte. Til revisjonen av prosjektbeskrivelsen til Forskningsrådet, vil OsloMet og prosjektpartnerne komme med en revisjon av metodebeskrivelsen. I den opprinnelige søknaden var det lagt opp til at utvikler No Isolation skulle gjennomføre spørreundersøkelser med ansatte, beboere og pårørende. I den reviderte utgaven tar OsloMet over denne oppgaven. Det vil gjennomføres spørreundersøkelser i tre omganger ved hvert av de 17 sykehjemmene som deltar i prosjektet. Første runde er baseline, og gjøres rett i forkant av utrullingen. Andre runde er etter 1-2 måneder. Tredje runde er etter 6 måneder. Spørreundersøkelsen vil (tentativt) bestå av tre forskjellige skjema per runde – ett for beboere, et for sykehjemansatte, og et for pårørende. Det legges opp til at beboerne får hjelp av ansatte ved sykehjemmet til å fylle ut sitt skjema.

## KOMMENTAR TIL NOEN AV PERSONOPPLYSNINGSKATEGORIENE:

Vi har krysset av for behandling av "Helseopplysninger". Med "Helseopplysninger" tenker vi på psykisk nedog oppstemthet, knyttet til spørsmål om ensomhet og meningsfulle sosiale relasjoner. Vi er altså ikke ute etter å behandle mer detaljerte opplysninger av biomedisinsk karakter, og vi behandler heller ikke konkrete diagnoser. (Det er dog verdt å nevne at ord som 'depresjon' og 'depressiv' kan brukes i både hverdagslige og spesialiserte termer, og at det ikke nødvendigvis fremgår av opplysninger om psykisk nedstemthet om det er snakk om 'klinisk depresjon' eller ei). Vi understreker også at prosjektet formål ikke er å fremme ny kunnskap om sykdom og helse, men om implementering og effekter av en ny kommunikasjonsteknologi.

## VEDLEGG ANGÅENDE TREDJEPERSONER:

Vi informerer om, og ber om samtykke til å behandle, informasjon om deltakere i utvalg 2 og 3 som er avgitt av andre. Dette ber vi om i de relevante informasjonsskrivene.

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# ANDRE VEDLEGG:

VI kommer til å benytte flere informasjonsskriv for utvalg 1 enn hva opplastningsportalen legger opp til. Det er behov for å sende ut informasjon til de 17 sykehjemmene som deltar, slik at alle er kjent med studien ("Informasjonsskriv sykehjem"). Vi kommer også til å bruke ulike spørreskjema i ulike faser av prosjektet. Vi har lastet opp spørreskjemaet for første runde i forbindelse med beskrivelse av utvalgene. Skjema for runde 2 og 3 skiller seg fra skjema i runde 1. Vi har derfor lastet opp skjema for runde 2 (vi laster ikke opp skjema for runde 3, da det er identisk med skjema for runde 2).

#### COVID-19 PROSJEKT:

Til sist understreker vi at prosjektet er støttet av Norges forskningsråd, basert på utlysningen "COVID-19 hasteutlysning: Innovasjonsprosjekt med privat-offentlig samarbeid (BIA-X)". Det er et ønske om snarlig oppstart fra alle parter, og vi ber derfor om å prioriteres i saksbehandlingskøen dersom dette er mulig og forsvarlig.

# INFORMASJON OM FORSKERE I PROSJEKTET:

I tillegg til Erik B. Rasmussen som er prosjektansvarlig, inngår følgende personer:

- Marit Haldar, professor ved Institutt for sosialfag, OsloMet
- Sehrish Akhtar, stipendiat ved Institutt for sosialfag, OsloMet
- Tonje Margrethe Gustavsen, masterstudent ved Institutt for sosialfag, OsloMet