



Solveig Bryne Castberg Stølan

Oslo 2019

**Remote Patient Monitoring:
The Role of and Impact on the Older Spouse**

Master's thesis in International Social Welfare and Health Policy

Oslo Metropolitan University

Faculty of Social Science

2019

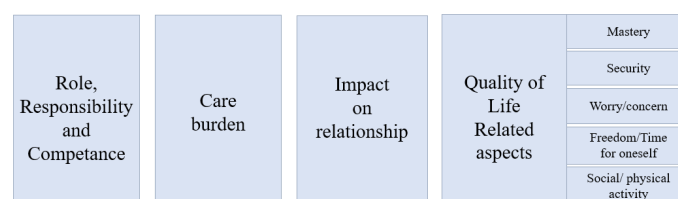
Abstract

Aims and objectives: This master thesis examines the topics of Welfare Technology and Family Caregiving. The Welfare Technology in focus is Remote Patient Monitoring. The aim of the study is to obtain better knowledge and understanding of the role of and the impact on the older spouse when their chronically ill partner receives Remote Patient Monitoring as a municipal service.

Background: Welfare technology and family caregiving are given central roles by the Norwegian Government in the building of a sustainable care model for the future. Family caregivers are also defined as important stakeholders in welfare technology. Furthermore, in the implementation of Remote Patient Monitoring in the Norwegian health care context, positive outcomes for family caregivers are sought and mentioned in policy- and project documents. However, the impact of this welfare technology on family caregivers is rarely addressed in empirically informed research.

Design: The study has a qualitative research design based on a conceptual, thematic framework developed as a part of this study. This framework is the foundation of the research questions, the data collection and the data analysis.

Method: This study applies a two-tier methodological approach. First a systematic document analysis was conducted to identify aspects relevant to examine when investigating the role of and impact on Remote Patient Monitoring on older spouses. The range of identified aspects were categorised into four main themes, forming this study's thematic framework:



The framework subsequently provided the following research questions: 1) What are the roles and the responsibilities of the spouse in Remote Patient Monitoring and do they have the needed competence?, 2) How does remote patient monitoring impact the care burden of the spouse?, 3) What is the impact of Remote Patient Monitoring on the relationship between the spouses? and 4) How does remote patient monitoring impact quality of life related aspects for the spouse?.

Secondly, semi-structured interviews were conducted with 7 informants. Five interviews were conducted with older spouses of recipients of Remote Patient Monitoring services. Two interviews were conducted with municipal health care personnel with first-hand experience with Remote Patient Monitoring.

Results and conclusion: At the point of introduction and entry into the remote patient monitoring service, the roles of the spouses appear to be considerable and is characterized by rationality and positivity. At the operational stage there are individual differences in the roles of the spouses. Some describe their involvement as limited to none, while others may be seen to be main operators in the domestic sphere. A wide range of different responsibilities and tasks the spouses may acquire was identified. In this study, all spouses acquired some form of task or responsibility related to the Remote Patient Monitoring. The contributions of the spouses appear well adjusted to their competence level and is generally not found to add a burden.

Reduced care burden and increased security are the most prominent impacts on the spouses. In both instances this is expressed to be a result of the sharing of responsibility for the ill spouse with the health care personnel at the response centres, and also the feeling of increased and improved medical follow-up of their partner. Among the other quality of life related aspects, this study has not found any distinct impacts on the sense of freedom or social and physical activity due to Remote Patient Monitoring. However, some experienced a lower level of worry. When it comes to dimensions of mastery, knowledge and control was found to increase, but independence and self-management showed less distinct changes.

To conclude, this study has found that the older spouses play an important role in the initial stage of the service. They are also contributors in the operational stage and may hold tasks that are critical to the sustainability of the service, regardless of the magnitude of their role. The main impacts experienced by the spouses as a result of Remote Patient Monitoring were increased security and care burden relief. Notably, both impacts seem to be products of the professional, human constituents of the service, and not primarily causes of the technology itself.

Keywords: Remote Patient Monitoring, Telecare, Telemedicine, Welfare Technology, Informal Care, Family caregiving, Older spouses, Avstandsoppfølging, Telemedisin, Teleomsorg, Velferdsteknologi, Familieomsorg, Eldre, Ektefeller

Oslo Metropolitan University, Faculty of Social Science
Oslo 2019

Acknowledgements

Almost two years ago, I started the academic journey that led to this thesis. I had been working with sustainability for many years, assessing how large health care corporations contributed to solving societal challenges such as aging populations and increase in chronic diseases, and their efforts to increase access to health care, for example through e-health solutions. I had for a long time had an urge to deepen my knowledge on these matters, and in turn this led me to a return to academia and OsloMet.

First, I would like to thank the Faculty of Social Sciences at OsloMet and the professors and the lecturers at the International Social Welfare and Health Policy Master Program, for an academically interesting and truly rewarding program. A very special thanks goes out to my supervisor Jardar Sørvoll at NOVA - Department of Ageing Research and Housing Studies. He has been a dedicated and enthusiastic supervisor, providing me with invaluable guidance, constructive advice and confidence in every part of the project.

Thanks to my fabulous husband for always making anything possible, for taking time at each and every step in this process to discuss small and large challenges, and for always providing relevant and sensible reflections and advice. Thanks to my parents for their enthusiasm and interest in my project, and for their scanning of journals and magazines for relevant articles and information. A special thanks my mum, who passed away last fall, for her reading of the initial sketches for this thesis and for her support in pursuing this. I am sad that I cannot share the final result with her, I think she would have been pleased and proud. Thanks to my three fantastic kids for cheering me along the past two years, and thanks to my mother-in-law for providing me with many hours of free time to work with this thesis.

I want to express thanks to Hilde Thygesen at VID Specialized University for introducing the participant-based framework for implementation of welfare technology, a framework that initially inspired this thesis, and also for her inputs in the process. Thanks to all of the people I have been in contact with as part of this study; in the municipalities, in the NGO's and in the academic sphere. I have been met with positivity, interest and helpfulness everywhere, for which I am very grateful. Also, a very special thanks goes to the persons who assisted in the recruitment of participants for my study.

Finally, my deepest of gratitude goes out to my informants. The information they so generously shared with me is the essence of thesis, and my heartfelt thanks go out to them for choosing to take part.

Table of contents

Abstract	3
Acknowledgements	6
Table of contents	7
Chapter 1 - Introduction	9
Topic for the thesis and preliminary research question	9
Background	9
The research setting and definition of terms	11
Remote patient monitoring	12
Family caregiving, spousal caregivers and older spouses	14
The purpose of and rationale for this thesis	16
Chapter 2 - Methodology and data collection	17
The aim of the study	17
Research strategy, design and methods	17
Document analysis and development of a thematic framework	18
Semi-structured interviews	20
Gaining knowledge of the field	20
Samples, recruitment and participants.....	21
Accessing the field	22
Recruitment activities.....	22
Participants	23
Data collection.....	25
Interview guide.....	25
The Interviews	26
Ethical considerations.....	27
Data analysis.....	30
Limitations of the study?.....	31
Chapter 3 - Research questions, literature and previous studies	32
Literature review	32
Formulating the final research questions based on the thematic framework.....	34
The Research Questions, Previous Studies and Literature	36
Chapter 4 - Results and findings	51
Chapter 5 - Summary and Conclusion	80
The Roles of the Spouse.....	81
The Impacts on the Spouse.....	82

Conclusion.....	84
Avenues for further research	85
References	86
Appendix 1 – Recruitment Poster.....	90
Appendix 2 – Interview Guides.....	91
Appendix 3 - Information letters and consent forms	97
Appendix 4 – NSD Approvals.....	105

Chapter 1 - Introduction

Topic for the thesis and preliminary research question

This study was based on the following preliminary research question:

What roles do older spouses acquire when their chronically ill partner receives Remote Patient Monitoring, and how are older spouses impacted by Remote Patient Monitoring?

This preliminary research question addresses two topics. It addresses the topic of welfare technology, looking specifically at Remote Patient Monitoring when provided as a service in the Norwegian municipal health care context to persons with chronic illnesses. Further it addresses the topic of family caregiving, looking specifically at the older spouses of persons receiving the service Remote Patient Monitoring.

In this chapter, I will first present the background of the study. Thereafter, the study's research setting will be outlined and described, followed by definitions and explanations of the terms and concepts addressed in the thesis. Finally, a summary will be presented along with an account of the rationale for this study.

Background

The current health- and care models in Norway are challenged by an aging population, increases in chronic diseases and a projected shortage of health care and care personnel. Currently the share of the population above 65 years makes up about 17 % of the population. In 2040, this share is expected to increase to more than 22 %. (Rogne & Syse, 2017, p. 19). Further, there is forecasted an increase in the recipients of nursing- and care services of around 46 %. (Rogne & Syse, 2017, p. 189)

The aging population, increases in chronic diseases and increased need for health care services will also lead to an increased need for health care personnel. However, projections show that there will be a growing shortage of health care personnel towards 2035, a deficit that ranges between 32 000 and 136 000 man-labor years under three different scenarios. (Roksvaag & Texmon, 2012, p. 5).

In this societal context, welfare technology, family and volunteer care and new service models are given central roles by the Norwegian Government in an effort to build a sustainable health care and care model for the future. This is future health care and care model is outlined in the white-paper “Future Care” (Morgendagens omsorg) (Ministry of Health and Care Services, 2012–2013, p. 45).

Welfare technology is in this white paper defined as follows¹:

«... First and foremost, technological assistance that contributes to increased security, safety, social participation, mobility and physical and cultural activity, and strengthens the individual's ability to cope with everyday life despite illness and social, mental or physical impairment. Welfare technology can also act as technological support for relatives and otherwise contribute to improving accessibility, resource utilization and quality of service provision. Welfare technology solutions can in many cases prevent the need for services or admission to an institution”(NOU 2011: 11, 2011, p. 99)

This is a useful but broad definition, and the concept of welfare technology can be described more specifically by its’ features in a welfare political context. Here, welfare technology is characterized by three features. Firstly, it is part of a care-context. Secondly, it targets primarily the users or recipients of the service, and older people and chronically ill are the main target groups. Finally, it enables services at a distance. (Thygesen, 2015, p. 6 & 10).

Welfare technologies can also be understood through different categories, as presented in the white paper, “Future Care”. These categories are: 1) Security and safety technology, for example security alarms with warning and localization technology, 2) Compensation and wellness technology, such as medicine dispensers, 3) Social contact technology, such as online-based support groups and 4) Technology for treatment and care, such as Remote Patient Monitoring (Ministry of Health and Care Services, 2012–2013, p. 111).

In 2013, on the basis of the white paper “Future Care”, a National Welfare Technology Program was established. The program is a collaboration between The Federation of the Municipalities (KS), the Directorate for eHealth and the Directorate of Health and it aims to contribute to the municipalities’ adoption of welfare technology. To date approximately 270

¹ All translations in this thesis are my own

municipalities take part in different welfare technology projects under the National Welfare Technology Program (Directorate of Health, 2019).

Family caregiving plays, and will continue to play, a major role in the caregiving model in Norway and family caregivers are recognized as an important resource by the authorities. A White Paper from 2018, “Leve hele Livet”, which is a policy reform targeting the elderly, states explicitly that it is also a reform for the family caregivers. The reform aims to take care of, support and help family caregivers to prevent exhaustion (The Ministry of Health and Care Services, 2018, p. 10).

In the most recent government platform, as in the previous one, there is a stated commitment to implement this reform for the elderly, and it is highlighted that attention should be paid to the fact that that relatives can have several roles, both as relievers, caregivers and decision makers in the treatment course. (The Office of the Prime Minister, 2019).

The introduction of welfare technology in Norway also targets outcomes for the family. This is illustrated in the definition of welfare technology which is presented in the government documents. The definition highlights that welfare technology can provide support for the family caregivers. Further, increasing their security and relieving the caregivers of worry are also outcomes from welfare technology that are expected in the white-paper, “Future Care” (Ministry of Health and Care Services, 2012–2013, p. 28).

Moreover, family caregivers are also defined as important actors or stakeholders in the welfare technology context. A framework developed by Bull-Berg also identifies family caregivers as one of six actors and organisations within the context of welfare technology, alongside the service recipient, the service provider, the government, private businesses and others. (Bull-Berg, Halvorsen, & Hem, 2015) and inclusion and involvement of important stakeholders, including family caregivers, are deemed a prerequisite for the successful implementation of welfare technology (Grut et al., 2013, p. 6).

The research setting and definition of terms

This section will describe the topics in focus in this thesis and present the research setting for the study. First, the welfare technology Remote Patient Monitoring will be explained along with an outline of its’ scope and characteristics in the Norwegian context. Thereafter, a brief outline of the role of family care in Norway will be presented, before moving on to looking at

the role of the spouse and spousal caregiving, in a general context as well as in relation to welfare technology and Remote Patient Monitoring specifically.

Remote patient monitoring

The Norwegian term for the welfare technology in question in this thesis is “Medisinsk Avstandsoppfølging” or just “Avstandsoppfølging”. There is a large variation of terms used for this technology or service, but the term that is found to be the closest in English is “Remote Patient Monitoring” (Intro International, 2018a, p. 68). Remote Patient Monitoring is consequently the term that will be used in this thesis.

Remote Patient Monitoring is a form of welfare technology that can be placed in the fourth category of welfare technology that was presented above; “Technology for treatment and care”. Further it may be defined as:

«... those activities / actions that allow the patient, outside the traditional places where the patient meets the health care professional, to obtain, record and share clinically relevant information about his or her health status electronically, with the purpose of providing information or guidance to the patient's self-management, and/or provide decision support for diagnosis, treatment or follow-up by health professionals” (Intro International, 2018b, p. 4)

There are a large number of different Remote Patient Monitoring projects in Norway. These are projects of various sizes and cover a variety of different diseases or conditions. The projects are operated both within the Specialist Health services and the Municipal Health services.

This thesis focuses on the form of Remote Patient Monitoring in Norway, which is provided by the municipalities and where the target groups are patients with chronic diseases such as COPD (*Chronic obstructive pulmonary disease*), Diabetes II and Cardiovascular diseases such as Heart Failure. Patients that receive these services are often above the age of 65 years (Intro International, 2018b).

More than 21 municipalities are involved in this form of Remote Patient Monitoring at present, mainly through two large projects. First, Remote Patient Monitoring has a designated project under the National Welfare Technology Program (Nasjonalt Velferdsteknologi Program). This project was launched in the autumn of 2016 and was carried out in Oslo (Grunerløkka, Gamle Oslo, St. Hanshaugen and Sagene), Trondheim (Trondheim, Malvik, Melhus, Midtre Gauldal and Klæbu), Stavanger and Sarpsborg.

The first test-phase of the project ended in 2018 and is continued with a second-test phase from 2018 – 2021. This second phase includes Oslo and Trondheim and an additional 6 new municipalities. 750 patients were recruited into the first test phase of the project.

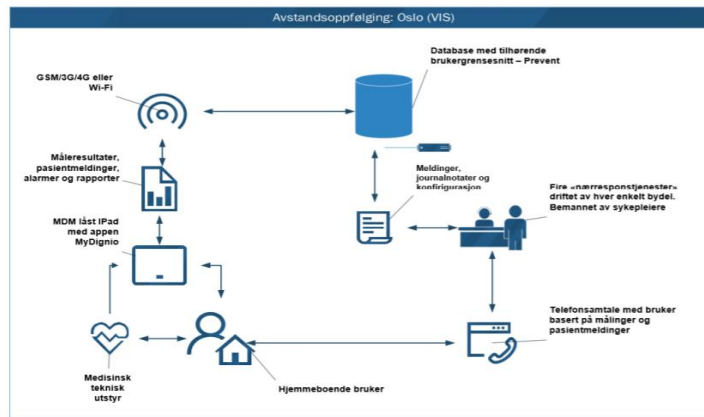
The other large Remote Patient Monitoring project is TELMA (Telemedical Solution for the county Agder/Felles telemedisinsk løsning på Agder). This is a project that aims to establish a common telemedical service of remote patient monitoring for all 30 municipalities in this southern county. As of February 2019 the project report of having recruited 64 patients (TELMA, 2019).

A person which receives Remote Patient Monitoring services will typically be provided with a tablet or an Ipad, as well as medical equipment suited for their particular needs based on the disease in question. The table below gives an overview over the equipment provided. This equipment include instruments for measuring blood pressure, blood sugar, temperature, oxygen saturation and pulse, as well as spirometry for measuring lung health, and weighing instruments.

Medisinsk teknisk utstyr (sensorer)	Funksjon
Nettbrett	Kliniske spørsmål
Blodsukkermåler	Glukose i blodet
Blodtrykkmåler	Systolisk/diastolisk blodtrykk, pulsfrekvens
Pulsoksymeter	Oksygenmetning, pulsfrekvens
Spirometer	PEF /FEV1
Vekt	Kilogram
Temperaturmåler	Kroppstemperatur

Source: (Intro International, 2018a)

Below the process of Remote Patient Monitoring is illustrated using a figure describing the process in Oslo as an example.



Source: (Intro International, 2018a)

Data collected from these instruments, as well as self-reported data on the person's own health situation, is reported through an application on the tablet on a regular basis to a response-center.

The health care personnel at the response-center receives the data, evaluates and acts upon the data, and contacts the patient by telephone, video-calls or by chat-functions on the tablet if required when assessing the information from the data.

Contact between the patient and the response-center can also occur as regular appointments at given intervals, and sometimes on an ad-hoc basis. There are different types of set-ups for the response centres in the Norwegian context. There are local response centres in the municipalities, response centre service delivered by private actors and more centralized response centres (Intro International, 2018b).

Family caregiving, spousal caregivers and older spouses

The scope of the informal caregiving in Norway is estimated to be of the same magnitude as the caregiving delivered by the public (NOU 2011: 11, 2011, p. 16). This informal caregiving is mainly provided by the family. In the 2017 Caregivers Survey, provided by the Norwegian interest group for caregivers, it was found that 41% of the family caregivers live in the same household as the one they care for and 22% of the caregivers have caring responsibilities for their partner. Overall, 63% of those who receive family care are more than 65 years of age,

and 21% of caregivers provide care more than 20 hours each week (Pårørendealliansen, 2017).

This thesis focuses on older spouses in a Remote Patient Monitoring context.

As mentioned previously, family caregivers are deemed important actors in the welfare technological sphere and examinations of role of and impact on all family caregivers are of both relevance and interest. This study has chosen to look at a smaller group of people among family carers, namely the older spouses.

This is a group among the family caregivers that resides with the user, and the Remote Patient Monitoring can have impacts in the domestic sphere that are specific to this sub- group of family caregivers. A co-resident such as a spouse will be exposed to the technology in a different manner than other family caregivers. The technology will to a larger degree will be integrated in their everyday life and affect their environment and domestic sphere.

Older spouses are also a natural focus point as the majority of users are over the age of 65. In the Norwegian Remote Patient Monitoring project under the National Welfare Technology Program, the average age of the users in the national project range between 64,6 years and 72 years.(Intro International, 2018a). As previously described, a main target group for welfare technology are also older people and the chronically ill (Thygesen, 2015).

Further, there is also a potentially large number of users of Remote Patient Monitoring that reside with a partner. The scope of users residing with a partner in the Norwegian context is not clear, but in a systematic review performed by Gorst et al, “Home Telehealth Uptake and Continued Use Among Heart Failure and Chronic Obstructive Pulmonary Disease Patients”, it was found that 66 percent of users in the study populations reside with a partner or another family member. It was also found here that the mean age of all participants in all the studies reviewed were 65 years (Gorst, Armitage, Brownsell, & Hawley, 2014, p. 326).

Further justifying the analysis of older spouses in this study is that this age group might also hold certain characteristics or vulnerabilities in regard to digital competence that is challenged when exposed to a welfare technological service.

Overall there is limited research on family caregivers, spousal caregivers or older spousal caregivers in the context of Remote Patient Monitoring. As already mentioned, family caregivers are argued to be one of six important actors within welfare technology (Bull-Berg et al., 2015), and in the two first of three reports commissioned by the Directorate of Health on the Remote Patient Monitoring Project it is stated that there are clear indications that

family caregivers are important actors when looking at both drivers and barriers for Remote Patient Monitoring. The same reports, however, also emphasize the lack of research on family caregivers role in, effect on and acceptance of distance monitoring. (Intro International, 2017, p. 46; 2018a, p. 67 & 68)

Literature and previous studies on family caregivers and other forms of welfare technology can provide insight into family caregivers efforts within this context. Findings show that the family caregivers *will* be impacted, that telecare *does* interact with family caregivers in the environment (Vallor, 2011, p. 256), and that family caregivers are found to be important to achieve sustainable use of telecare (Karlsen, Moe, Haraldstad, & Thygesen, 2018, p. 11). Family members may also be included in the new forms of labour processes resulting from reconfiguration of health work and act as “interpretive intermediates” (Andreassen, Dyb, May, Pope, & Warth, 2018, p. 41 & 42), and they may be provided with new tasks and responsibilities that do not necessarily match their capacity and competence, but may also provide increased independence and security (Thygesen and Moser, 2014, pg.10).

The purpose of and rational for this thesis

The purpose of this study is to shed light on the consequences of welfare technology for the family caregiver, represented by the older spouse. Although, family caregivers are commonly defined as important actors and stakeholders in the implementation and continued use of this welfare technology, there is limited research addressing family caregiving and Remote Patient Monitoring, and further research is called for.

Further, in the implementation of Remote Patient Monitoring in the Norwegian health care context, positive outcomes for family caregivers are explicitly stated in policy- and project documents, but these aspects and outcomes are also to a limited degree addressed in research. In addition, studies on other forms of welfare technologies and family caregivers find that impacts on the family caregiver occur when implementing welfare technological solutions.

Considering the aspects mentioned above and keeping in mind the societal context, where the importance of both welfare technology and family caregivers in a sustainable future care model is emphasized, a survey of the efforts of an important actor and stakeholder can be argued to be warranted.

Chapter 2 - Methodology and data collection

The aim of the study

Based on the preliminary research question, presented in the beginning of Chapter 1, the aim of the study is twofold.

- 1) It aims to examine the role the spouse might acquire when their chronically ill partner receives Remote Patient Monitoring as a municipal health care service.
- 2) Further it aims to investigate the possible impacts of Remote Patient Monitoring on the spouse.

In the following the study's research strategy, the research design and the research methods applied to achieve the aims of this study, will be described.

Research strategy, design and methods

The research strategy used for this study will be qualitative research. The aim of this study is to examine and obtain a deeper understanding of the role of the older spouses and how they are impacted by Remote Patient Monitoring, and also identify the relevant aspects to examine in this regard. A qualitative research strategy is therefore considered best suited to achieve the aim of the study.

Research design provides a framework for the collection and analysis of data (Bryman, 2012, p. 46). The study has a qualitative research design based on a conceptual, thematic framework developed as a part of this study. This framework is the foundation of the research questions, the data collection and the data analysis. This framework will be described in more detail in the coming sections.

Research method is the technique that is applied for the collection of the data and can be conducted in various ways within qualitative research (Bryman, 2012, p. 46). This study is based on a two-tier approach. First a document analysis was conducted, followed by semi-structured interviews of relevant informants.

Document analysis and development of a thematical framework

Document analysis as a method in qualitative research that can be defined as:

“a systematic procedure for reviewing or evaluating documents (...) where data is examined and interpreted in order to elicit meaning, gain understanding, and develop empirical knowledge”(Bowen, 2009, p. 27).

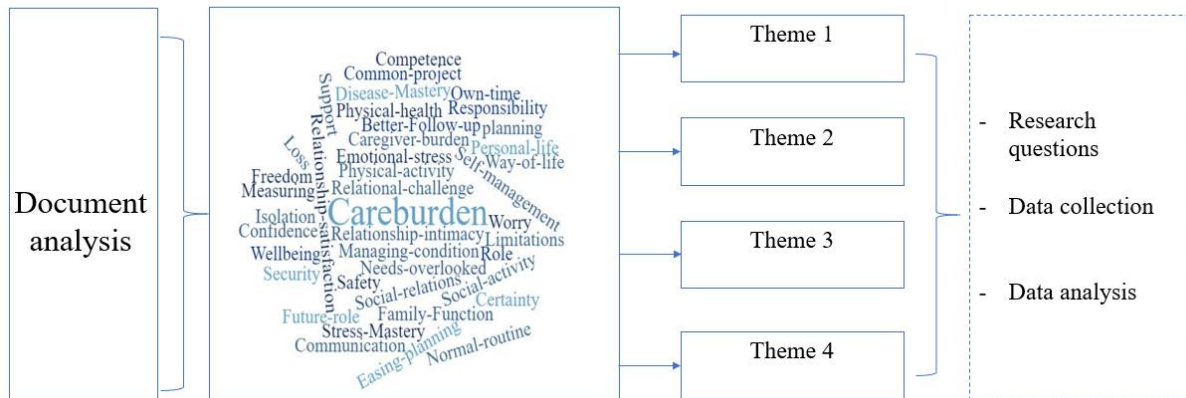
The purpose of this document analysis was to, in an informed manner, identify themes, topics and aspects relevant to examine when investigating the role of and impact on older spouses under Remote Patient Monitoring. The document analysis was conducted on a range of different official and government documents that are relevant in the context of welfare technology, as well as various project reports and academic literature. Relevant academic literature was identified through the literature review described in more detail in Chapter 3. The document analysis investigated 31 different documents in total.

The table below outlines the distribution of these documents into different categories of documents.

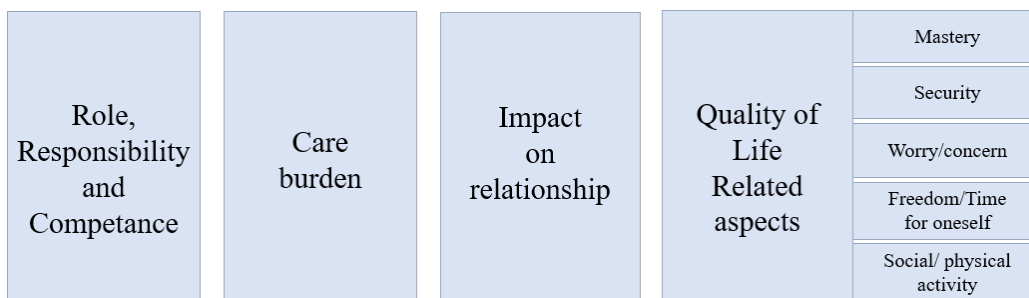
Type of documents	Number of documents
White Papers (Norwegian)	2
Official Norwegian Reports (NOU)	1
Other government documents	3
Project Reports and from the Norwegian RPM initiatives, and related documents/information	8
Academic literature on Remote Patient Monitoring and welfare technology	17
Total	31

On the basis of the analysis of these 31 documents, more than 50 themes and topics considered relevant to examine in the thesis emerged. The range of identified themes and topics were compiled, registered, sorted and finally categorised into four main themes. These four main themes formed the basis for the study’s conceptual and thematical framework,

a framework that informed development of the four final research questions, as well as providing the basis for both the data collection and the data analysis.



The main themes, identified in the document analysis as relevant to investigate when examining the role of and impact of remote patient monitoring on the older spouse, were the following:



These for main themes subsequently provided the study with these four research questions:

Research question 1:

What are the roles and the responsibilities of the spouse in Remote Patient Monitoring and do they have the needed competence?

Research question 2:

How does remote patient monitoring impact the care burden of the spouse?

Research question 3:

What is the impact of Remote Patient Monitoring on the relationship between the spouses?

Research question 4: How does remote patient monitoring impact Quality of Life related aspects for the spouse?

Semi-structured interviews

The research method chosen in the collection of data is semi-structured interviewing. In a semi-structured interview, the interviewer has a number of fairly specific questions in a questionnaire or an interview schedule, but the interviewees have flexibility in how they reply. The questions in a semi-structured interview will be asked with similar wording in all interviews. The sequence of questions can be defined, but the interviewer may also vary the sequence of the questions and also has the possibility to elaborate on responses viewed as significant replies. (Bryman, 2012, p. 212 & 471).

It was found that this methodological approach matches the preliminary research question best, and in particular for the spouses, as interviews “...offer a rich source of data which provide access to how people account for both their troubles and good fortune.” (Silverman, 2011, p. 203).

It can however, in a methodological discussion, be debated if verbal accounts such as interviews are of sufficient value in explaining people's actions, as verbal accounts are argued to be “overly individualistic and abstracted from lived experience” (Jerolmack & Khan, 2014, p. 178). Another central element to consider in a methodological discussion, when using qualitative methodology and interviews with a limited number of individuals, is the question of to what extent conclusions based on small samples may be generalized to other settings. (Bryman, 2012, p. 406)

Gaining knowledge of the field

Building up to and during the master thesis process, I took several steps to increase my overview of the field. As a part of the Master Program leading up to the thesis, one of the obligatory 10 ECTS master program-subjects was taken at VID Specialized University. The master subject is called, “Welfare Technology for Elderly”, and is part of the VID's Master's Degree Health and Care Service Development for the Elderly.

As part of this course, I also took part in demonstrations of a wider array of welfare technology during a field visit to Alma's House. Alma's House a knowledge and visiting center for assistive technologies and welfare technology, which is a part of the Development Center for Nursing Homes and Home Care Services in Oslo.

In addition, meetings and conversations with three different municipalities that have implemented Remote Patient Monitoring as a service were conducted during the thesis-process. One of these meetings also included a demonstration of the Remote Patient Monitoring Technology. Furthermore, one health care technology conference and four different seminars on Remote Patient Monitoring, including one research seminar, were attended during the course of the study. Conversations and discussions with academic researchers in the field were also conducted as part of the thesis process.

Samples, recruitment and participants

In this study, two groups were interviewed in order to investigate the research questions.

Sample I: Older spouses.

This first sample satisfy the following eligibility criteria; 1) they are spouses or partners of patients who are chronically ill and are receiving remote patient monitoring services and 2) they are 65 years of age or older.

Sample II: Municipal health care personnel.

This second sample met the following eligibility criteria: 1) Health care personnel within municipal care services with first-hand experience with remote patient monitoring, and 2) who also had perspectives on the role of and the impacts on the spouses/ partners within this service.

The study conducted 7 interviews in total.

- 5 participants were interviewed in Sample I, older spouses.
- 2 participants were interviewed in Sample II, health care personnel.

I had an initial goal of interviewing up to 10 informants, as this was considered both sufficient to examine the research questions and also a manageable number of informants for the resources and stipulated time for the master thesis. As will be explained in more detail in a later section, there were challenges in recruitment of informants, and the study was able to access 7 informants in the end, slightly less than the original aim.

Although it was desirable with a slightly larger number of informants, the quality of the interviews and the richness of the qualitative data material, the data was considered sufficient to achieve the aim of the study.

Accessing the field

Accessing the field for this study was done by making contact with a number of different stakeholders within Remote Patient Monitoring in Norway.

The main strategy was making contact with the relevant municipalities and Remote Patient Monitoring or welfare technology contact persons in these municipalities. In addition, contact was made with a number of relevant non-governmental organisations. These covered interest groups for the diseases in focus in the Remote Patient Monitoring projects/services. These organisations were The National Association for Heart and Lung Disease (LHL), The Norwegian Diabetes Association (Diabetesforbundet) both centrally and locally, as well as other relevant interest groups such as The Carers Alliance (Pårørendealliansen) and Association of Pensioners (Pensjonistforbundet).

Contact was made with scholars that are experienced in welfare technology and Remote Patient Monitoring research. In addition, suppliers of the Remote Patient Monitoring technology were also contacted in this regard.

In total 21 municipalities and 11 NGO's and 2 companies were contacted as part of the efforts of accessing the field. Contact and conversations were established with more than 90 % of the contacted units. The conversations consisted of more than 200 contact points, mostly by e-mail, but also by telephone.

Recruitment activities

The recruitment strategy for this study consisted of several approaches, all of which were approved by the NSD (Norwegian Centre for Research Data).

1. Recruitment efforts through welfare technology/remote patient monitoring contact persons in the municipalities (n=21)

Key persons in most of the municipalities that have delivered, delivers or are in the process of implementing Remote Patient Monitoring were contacted in respect to assistance in the recruitment of participants for Sample I. Furthermore, a selection of these persons were also asked at a later stage in the process to be participants in Sample II.

2. Recruitment efforts through NGO's (centrally and regionally) and Companies (n =11)

Non-Governmental Organisations focusing on either the diseases in focus for Remote Patient Monitoring or on the relevant demographic group were contacted for assistance in recruitment. Those who had the opportunity, assisted in passing on information on the study and recruitment information by mail to their internal as well as external networks.

3. Recruitment efforts through recruitment posters at relevant locations (n = 8)

Recruitment posters were hung in eight relevant locations, such as day centres for elderly, in two different municipalities with large numbers of current and prior Remote Patient Monitoring users.

Participants

In Sample I all participants were recruited via the first method of recruitment; **“Recruitment through welfare technology/remote patient monitoring contact persons in the municipalities”**, including through one general practitioner.

If involved directly in Remote Patient Monitoring, the municipal personnel that were contacted aided in obtaining contact with possible participants themselves. If not, the enquiry for assistance to recruit was passed on to health care personnel, often in the response centres.

The telephone numbers of the spouses, who expressed an interest in participating, were provided by the contact persons or health care personnel. The potential participants were then contacted by the researcher via telephone, given further information on the study. A convenient location, date and time to conduct the interview was then arranged.

Five participants for the study were recruited in Sample I. A sixth person expressed interest in participating but withdrew from the study prior to the interview. The five participants were all retirees, three were men and two women. Two lived in municipalities with populations lower than 10 000, one in a municipality with a population between 20 000 and 49 999, and the two others in municipalities with populations larger than 50 000. Geographically the participants represented both Southern Norway, Eastern and Central Eastern Norway. Their experiences with Remote Patient Monitoring ranged from 3 months to 1,5 years.

Recruitment of a sufficient number of informants into Sample I proved to be challenging, despite extensive efforts to access possible candidates. A main challenge in recruitment is

considered to be the limited number of persons in Norway currently receiving Remote Patient Monitoring as a service, as it is still mainly a project-based service. In the Remote Patient Monitoring Project, which is part of the National Welfare Technology Program, there were approximately 750 patients enrolled in the project, 458 of which were active patients in June 2017 (Intro International, 2017, p. 4). The telemedical project in Agder had 54 users as of February 2019 (TELMA, 2019).

Many of the users might also be living without a spouse, reducing the potential population for this study even further. According to figures from a systematic review of studies on Remote Patient Monitoring, 34% of the Remote Patient Monitoring patients in the study's population were living alone (Gorst et al., 2014, p. 326).

Studies also indicates that there is a underrepresentation of older people in aging research, because of challenges related to recruitment of older persons due to factors such as health problems and social and cultural barriers (Karlsen et al., 2018; Mody et al., 2008). During the process of the thesis the challenge of accessing older spouses and family caregivers was also confirmed when talking to researchers in Norway who had experience from family caregiving research and recruitment of family caregivers to larger commissioned research projects.

Other restrictions on recruitment is related to the limitations in the opportunities to assist on the side of the contact persons in the municipalities. Assistance here requires that the personnel both know the spouses of their Remote Patient Monitoring recipients sufficiently and are comfortable asking potential candidates to participate. Another critical precondition for successful recruitment is that these persons must have both the time and resources to assist. This is not always the case. As a response to the recruitment challenges in Sample I, the study was expanded with an additional sample of informants in January 2019.

The second sample of this study consisted of municipal health care personnel with direct experience with remote patient monitoring as a municipal service. These participants also had to have perspectives on the role of the older spouses. The expansion to include a second sample was as stated, initially a response to challenge of recruitment of participants in Sample I, but also showed to contribute to valuable viewpoints into the study from experienced municipal health care personnel.

Two persons were interviewed in Sample II. Both persons have direct experience with Remote Patient Monitoring from municipal health care, and both have experience from and are a part of response centre functions. They also had perspectives on the role of and the

impacts on the spouses based on their experience in the field. They are representatives of two different municipalities in Norway, one with a population below 10 000 and the other with a population above 50 000.

Data collection

Interview guide

The qualitative data from the semi-structured interviews were collected according to a pre-developed interview guide. An interview guide provides a framework for the interview and provides the researcher with a list of questions or relatively specific topics to be covered. (Bryman, 2012, p. 471). The interview guides used for this study was informed by and built around the thematical framework that was developed as part of the study.

The interview guide used on Sample I consisted of approximately 30 questions. The first few questions were primarily factual and designed to provide an overview of the interviewee's life situation. The initial questions were also designed to be easy to answer, assisting in establishing the conversation and creating a good atmosphere for the interview. The next questions in the interview guide were designed to be open-ended, in order to make the interviewee talk independently about their experiences. Some of the questions in the interview guide were also supplied with follow-up questions and cues for conversation to enable elaboration and deliberation.

The interview guide used for Sample II consisted of 20- 25 questions. This guide was also built up around the study's thematical framework and covered the same categories and themes as the interview guide for Sample I, however the questions were now designed to capture the interviewees perspectives and impressions of the role of and impact on the older spouse. The questions in this interview guide were asked in forms such as "Do you have the impression that...", "Is your experience that...", "To what degree do you find that.." and "Based on your experience with the users, how do you perceive...".

Both of the two interview guides were adapted during the data collection process to increase the quality of the interviewing. Mainly the chronology of the questions was altered, but also the introduction to and wording of some of the questions were amended. The interview guides can be viewed in Attachment 2.

The Interviews

The interviews in both Sample I and II were conducted between November 2018 and April 2019. All 5 informants in Sample I were provided with written information letters, and their spouses (the Remote Patient Monitoring user/recipient) were given a separate information letter. The information letter's contents were summarized orally before the interview started, emphasizing aspects such as consent, anonymity and the right to withdraw at any time. Finally, the interviewees were given the possibility to ask question about the study before the interview started. Two of the interviews from Sample I were conducted in person, in the homes of the informants. When conducting interviews, there is a need for a space where the interviewer and the interviewee can be relaxed, be able to talk and be undisturbed. This may be difficult to achieve, but conducting the interview in the interviewees own homes is often most convenient for them, and has the best potential for privacy (Byrne, 2004, p. 203).

The three other interviews in Sample I were conducted over the telephone. The approach of telephone interviewing differs from what Bryman calls an archetypal interview of informants in social research, but is deemed a "possible departure" from the archetypal interview (Bryman, 2012, p. 213). Bryman points to several limitations when telephone interviewing, compared to the personal interview. One of the limitations is that there is some evidence to suggest that telephone interviews are less suited for the asking of questions about sensitive issues, such as health, but it is stated that the evidence is not entirely consistent in this regard. Among other limitations mentioned is the lack of observation of the interviewee and being unable to respond to "signs of puzzlement or unease" (Bryman, 2012, p. 215). Both limitations were kept in mind when conducting the telephone-interviews.

Moreover, Bryman also mention several advantages when it comes to telephone interviewing. One of these advantages are that they are they are quicker and cheaper to administer, a factor that is said to be especially relevant when the sample is geographically dispersed (Bryman, 2012, p. 214). Two of the telephone interviews were conducted over the telephone due to practical reasons, and saved time otherwise needed for long distance travelling to conduct the interviews in person. The third telephone interview was done at the wish and preference of the informant.

The five interview sessions in Sample I lasted between 47 minutes and 24 minutes, with an average of 40 minutes. The interviews that were conducted over the phone were the shortest ones, lasting 34 minutes, 30 minutes and 24 minutes respectively.

Two informants were interviewed in Sample II. Both were provided information letters prior to the interviews. One of the interviews was conducted over the telephone and the other was conducted in person in a municipal office space. The interviews lasted 30 minutes and 45 minutes respectively.

Recording and transcription

Recording of the interviews were done with an audio recording device, Sony ICD-PX370 recorder. The recordings from the interviews were transcribed using the Hyper Transcribe-software for Windows. Hyper Transcribe is a software that allows for control over the playback of the audio recordings through accessible keyboard controls, looping of playback and quick keyboard commands. (Researchware.com, 2019).

The full contents of the interviews were transcribed, but names of persons, municipalities, cities and project were anonymized in the written transcription. Transcriptions of the recordings were conducted within two days of the interviews, but preferably the same day or the day after the interview. The audio-recordings of the interviews were then deleted from the audio-device within these two days.

Ethical considerations

NSD approval

This study's data collection was approved by the Norwegian Centre for Research Data (NSD), on 30 October 2018. The project reference number is: **199770**. The amendment of the project to include an additional sample was approved 7 January 2019.

Evaluation of REC-approval requirement

The Regional Committees for medical and health research ethics (REC) shall provide approval for medical and health research projects. Among activities that require approval from REC are student assignments with the purpose of acquiring new knowledge about health and diseases (REC - Regional Committees for Medical and Health Research Ethics, 2019)

Investigations were conducted in order to decide if the project required approval from the Regional Committees for medical and health research ethics. The investigations included e-mail and telephone dialogue with the REC in April 2018. This written and oral dialogue with the REC provided information that was formed into a checklist, which became subject for evaluation. The results of the checklist indicated that approval was not required. The NSD was also consulted in April 2018, and although stating that it is the REC that had the final

assessment if a study requires approval, they did not see that this was required based on the information provided.

In further investigations, different studies and master thesis with similar thematic as this study, were examined to assess approval requirement through the precedence from other studies. The relevant studies examined did either not refer to REC approval requirements in their methods section, or had been assessed not to require approval (Hesleskaug & Tuft, 2016; Karlsen et al., 2018; Thygesen & Moser, 2014). Finally, advice on the requirement for approval was sought with three different researchers that had experience with the REC and requirement for approval, all of which, based on the provided information, did not see that this study required approval from the REC. Based on the results of the investigations outlined above, the study was not found to require approval.

Approaching informants

Informants were approached in a manner that did not breach their right to privacy and in a manner that was preapproved by the NSD. Recruitment efforts were planned to be expanded in November/ December 2018 by recruitment postings on relevant Facebook-groups. This approach was an addition to the initial strategy presented to the NSD and the addition was approved by the NSD on 27 November 2018. The approval came with certain conditions in order to secure confidentiality and privacy of potential participants. The first condition was to be clear in the recruitment text that all contact regarding interest to participate was not be e-mailed directly to the researcher and not make use of the comments-field on the Facebook-posting. The second condition was to regularly go through the comments given in the posting and delete comments that could breach confidentiality and privacy. Being unsure of, if the Facebook-post was shared repeatedly by others, it was possible to uphold the last condition in a sufficient manner and safeguarding confidentiality and privacy, it was chosen not to go further with this recruitment strategy.

Information letters, consent and right to withdraw

All informants were provided with detailed information letters describing the study and given the possibility to ask questions prior to providing consent. In Sample I, it was required to provide the participants spouse, the user of remote patient monitoring service, with a separate information letter explaining the study and their rights. This was a requirement due to the fact that the spouse can be identified indirectly by being the partner of the participant, as well as the fact that their names and information on health conditions may appear in the interview situation. Due to the fact that it is the user's spouse who is in focus in this study and the information gathered on user themselves are sparse, consent was not required. The consents

of the informants were collected before or at the time of the interviews. The consents were given in writing as a general rule. However, in the case of two informants in Sample I who were interviewed over the telephone, consents were given orally in the beginning of the interview session and documented by the audio-recorder. This solution for documenting consent was advised and proposed by the NSD per telephone on January 21 2019. This was done as an effort to overcome possible restrictions on the side of the informants and to lessen unnecessary tasks for them; printing the documents, taking screenshot, e-mailing signed documents or having to post the documents.

The right to withdraw at any time was specified both in the information letter as well as in the interview setting and emphasized in particular for the informants in Sample I. The information letters and consent forms can be viewed in appendix 2.

Confidentiality and anonymity

All data collected was treated with confidentiality, and all data was anonymized when transcribed. Information that contained personal identifiable data such as contact details and written consent forms were kept and stored separately from the research data. There was no information linking the research data and the information containing the personal identifiable data. In the interviews with informants in Sample II no information was collected that could identify individual patients, their spouses or reveal confidential information. The NSD also recommended that attention was paid to the fact that not only names but also identifying background information must be omitted, such as age, gender, location, diagnoses and any special events, as well as careful use examples during the interviews in this regard. This was adhered to.

Data protection and storage

All personal identifiable data has been stored separately from the research data. All data has been stored on units with access restrictions. First level transcriptions and audio-recordings, including the recordings containing oral consent, has not been stored on a local unit, but on a central server provided by the university. Written consents have been safeguarded in a separate folder under lock and key.

Data analysis

The methodology framing the analytical strategies of this study is a thematic framework. The interview guides were as previously mentioned built up around the study's thematic framework and the transcriptions were therefore to a large degree thematically organised from the beginning of the analysis process.

Before commencing with the analyses, the thematic organisation was reinforced by creating analysis-documents of the transcribed interviews, further organised according to the thematic framework. In these documents the main themes and sub themes were organised into tables and given separate pages per theme, in order to more easily conduct comparisons between the interviews at a later stage in the analysis process. The textual fonts and spacing between the lines were also adjusted at this point to increase readability and allow for sufficient workspace in the document for the analysis and coding process.

The analysis process consisted of several steps. Firstly, all interviews were read through for familiarization of the interview contents, without marking or coding passages. The interviews of Sample I were read through first, in order to build the first impressions on the basis of the older spouses themselves. Interviews from Sample II were read second. After all interviews had been read through a first time, notes were taken of first impressions of both features with the different informants and of commonalities and differences between them. Next the interviews were gone through again, on theme at a time, but examining the whole of the documents in its full content each time, in order to identify contents relevant for a given theme anywhere else in the documents. Coloured markers and coloured page markers, one colour for each theme, were used in this process to underline and identify relevant passages in the texts. In this process Sample I – documents were gone through first, Sample II secondly.

Following this activity, coding of passages and identification of additional sub-themes were conducted. Coding is a process whereby “the data are broken down into their component parts and those parts are then given labels. The analyst then searches for recurrences of these sequences of coded text within and across cases and also for links between different codes” (Bryman, 2012, p. 13). The notes of the first impressions from the first stage of familiarization aided in the coding of the interviews. Next, codes, passages and sub-themes identified in the previous step were organised and categorized forming the basis for the final analysis and interpretation of the findings. The last step consisted of establishing documents per theme, collecting and organising passages from the text that were relevant for the sub-topics and units of the analysis. This final step provided grounds for writing out the findings.

Limitations of the study?

Naturally, the study has some limitations when it comes to explanatory power. The first limitation is the overall critique of qualitative methods and their limitations regarding generalisation of research findings. However, compared to quantitative approaches in which generalisation of findings is possible, the epistemic advantage of an interview can be that it gives access to the participant's "understanding of the world and their experiences" (Risjord, 2014, p. 58) and the interviews conducted here, provided the study with rich and a comprehensive amount of data.

A second limitation can be argued to be the challenge of recruitment of participants. A somewhat larger number of participants in the study had been desirable. However, the challenge of recruitment of older informants was met with the strategy of including a second sample to the study, which also provided the study with an additional viewpoint on the role of and impact on the older spouses. Thereby, a total of 7 interviews were conducted, providing the study with a rich data.

A third limitation related to the samples can be the way in which older spouses were recruited. It was the contact persons in the municipalities who recruited the informants, and this might have impacted on the profile of the informants, perhaps to some degree favouring informants with a positive attitude both towards the technology and to study-participation. However, as the study showed, informants had varied roles and levels of enthusiasm, and represented both genders and different municipalities of varying sizes and geographical regions.

It is also important to recognize the complexity of measuring aspects related to quality of life, relationships and care burden. This study aims to shed light on these aspects in the context of remote patient monitoring, but does not aim to, or is able to, assess the full impact on remote patient monitoring on the older spouses. However, this study and the thematical framework developed here might generate hypotheses and be a point of departure for survey-based research, that may provide a more representative and richer picture of the impact of remote patient monitoring (or other forms of welfare technology) on family caregivers.

Chapter 3 - Research questions, literature and previous studies

Literature review

My literature review was conducted using Oria and EBSCO-host. Oria is a joint search portal that covers material found in Norwegian academic and research libraries. EBSCO-host is a database-host covering a variety of databases, such as Academic Search Premier, Academic Search Ultimate, Business Source Elite, Cinahl, E-book-Collection, EconLit, Educational Source, ERIC, Food Science Source, GreenFILE, Medline, SocINDEX, and Teacher Reference Center.

The literature review conducted in Oria and EBSCO-host was done twice. The first review was conducted in June 2018 and the second review in August 2018. The reason for conducting two literature searches in the databases was the large variety of terms used for “remote patient monitoring”. The findings from the first round of searches gave input to other terms used in the international literature for this particular welfare technology. These terms were consequently applied in the second round of literature review, in order to increase the quality and accuracy of the literature search.

A variety of terms were also used in the literature in regard to the terms “spouses”/ “partners”, and input from the first review was also used to increase quality and accuracy of the searches in the second round of literature search. The searches in the review were conducted using both English and Norwegian search-words.

Three main lines of enquiry were pursued in the literature review. The first line of enquiry covered literature and studies addressing being the spouse of or family caregiver for a person receiving Remote Patient Monitoring. The Second line of enquiry targeted literature addressing being the spouse of or family caregiver for a person receiving some form of welfare technological service. The third line of enquiry targeted literature addressing being the spouse of or a family caregiver for a chronically ill person. This third line of enquiry aimed to reveal relevant states and issues on the side of the spouse which a welfare technological service has the potential to impact.

The table below provides an overview of the search words and combination of search words used in the review.

1		2		3
<ul style="list-style-type: none"> - REMOTE PATIENT MONITORING - TELEHEALTH - TELEMEDICINE - TELEMONITORING - TELECARE - E-HEALTH/EHEALTH - WELFARE TECHNOLOGY - VELFERDSTEKNOLOGI - AVSTANDSOPPFØLGING - TELEMEDISIN - TELEOMSORG 	and	<ul style="list-style-type: none"> - RELATIVES - FAMILY - FAMILY CAREGIVERS - SPOUSES - PARTNERS - INFORMAL CARE - PÅRØRENDE - FAMILIE - EKTEFELLE - PARTNER 	and	<ul style="list-style-type: none"> - CHRONIC DISEASE - CHRONIC ILLNESS - COPD - DIABETES - HEART FAILURE - KRONISK SYKDOM - DIABETES - KOLS - HJERTESVIKT

Manual searching for literature in reference lists has also been an important approach for identifying relevant literature for this study. A limited amount of literature on this topic, combined with the large spectre of different terms used for the welfare technology in question was found to restrict results from the database searches. Hence, identifying relevant literature through manual searches proved to be a productive approach.

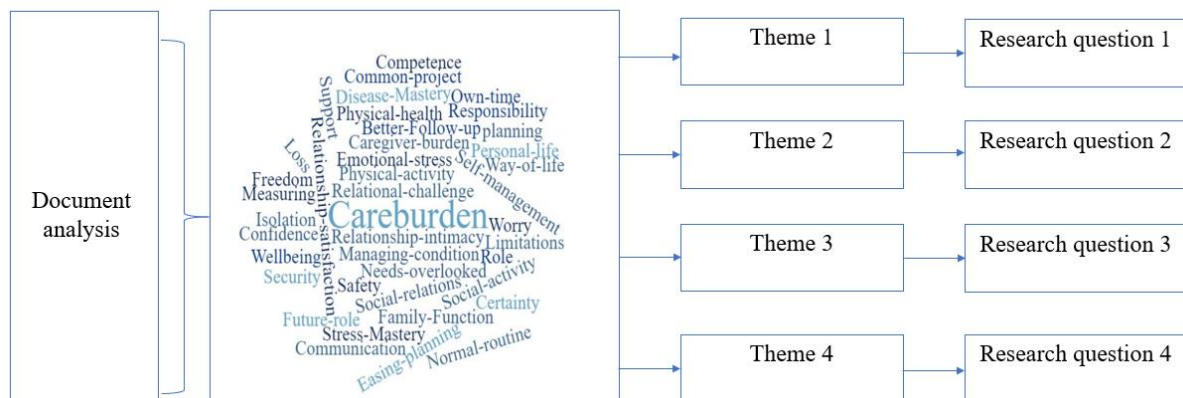
The manual searching was mainly conducted by going through the reference lists of the literature found in the review, but also by going through the reference lists of Norwegian reports, white papers and research reports on Remote Patient Monitoring in Norway. Relevant literature was also gathered when participating in the Master-subject course “Welfare technology for elderly” at VID Specialized University.

Formulating the final research questions based on the thematical framework

The research questions of this study are informed by previous studies and research, other relevant literature on welfare technology, as well as a number of relevant government reports, through the thematical framework developed on the bases of the document analysis.

As previously mentioned, a document analysis was conducted based on the preliminary research question, with the purpose of identifying informed and relevant themes and topics to examine when investigation the role of and impact on older spouses under Remote Patient Monitoring. The document analysis further informed the development of a thematical framework, consisting of four main categories of themes.

This thematical framework and it's four main themes provided the basis for the four final research questions.



There are not necessarily sharp boundaries between the four main categories, and they might also partially overlap and partly address related concepts, but the four main themes in the framework are the following:



Based on the preliminary research question, and the themes of the framework, the study's four final research questions were formed:

Research question 1:

What are the roles and the responsibilities of the spouse in Remote Patient Monitoring and do they have the needed competence?

Research question 2:

How does remote patient monitoring impact the care burden of the spouse?

Research question 3:

What is the impact of Remote Patient Monitoring on the relationship between the spouses?

Research question 4:

How does remote patient monitoring impact Quality of Life related aspects for the spouse?

The Research Questions, Previous Studies and Literature

In the following section the four research questions of this study will be presented and further described. The most important scholarly contributions relevant for each of the research questions will also be presented along with a discussion of different findings in the literature.

Research question 1: What are the roles and the responsibilities of the spouse in Remote Patient Monitoring and do they have the needed competence?

This research question aims to examine the role, responsibilities and competences on the side of the spouse which arises as a result of the introduction of the technology, and if these are aligned with the competences of the spouse. Assessing the roles, involvement and efforts, and the duties, tasks and responsibilities of the family caregiver in a welfare technology and remote patient monitoring is a concern and point of focus in several academic studies, all of which will be presented in below. The relevance and importance of this research question is also found in the recently published work of Moser and Thygesen, who have developed a framework that focuses on the human, value-based and social consequences of the implementation of welfare technology, emphasizing the participants within the welfare technology. (Moser, 2019, p. 45). This framework provides both rationale for assessing the role of spouse in Remote Patient Monitoring, as well as some relevant factors to assess².

The framework builds on a theory presented by Akrich in 1992, which argues that all technologies come with a given script that defines the setting of the technology. The script defines who the actors or stakeholders are and the relationship between them, and underlines the importance of the actors for the successful and intended use of the technology:

“Technical objects define a framework of action together with the actors and the space in which they are supposed to act” and further “(..)to be sure, it may be that no actors will come forward to play the roles envisaged by the designer or users may define different roles of their own. If this happens the object remain a chimera”(Akrich, 1992, p. 209).

² This academic work was not published before this master thesis was at the end of its process, however the framework was introduced during participation at the master subject “Welfare Technology for Elderly” at VID Specialized University in January – March 2018, and became a portal to the field and inspiration to this part of the study.

In their framework, Moser and Thygesen stress the need for a participant- oriented introduction of welfare technology, in which the involvement and needs of the different actors in the technology should be assessed to secure successful implementation. Two of the six core questions presented as a part this framework is how the roles, tasks and responsibilities are distributed, and which competence, capacity and other resources are required (Moser, 2019, p. 56).

The factors that will be examined in this research question are the roles and the responsibilities the spouse may acquire under Remote Patient Monitoring, and attempt to assess if they have the required competence.

Roles and responsibilities. Studies found in the literature review tell different stories about the role and responsibility of the spouses in Remote Patient Monitoring. In a qualitative study by Bregendahl and Laustsen looking at the family caregivers' experiences in a heart patient's telemedical rehabilitation program, it was found that the spouses to a limited degree were involved in the use of the telemedical equipment. According to the study, the spouses experienced that the patients themselves were motivated to be active in their own measurements (Bregendahl & Laustsen, 2016, p. 140).

In another qualitative study looking at different home care measures for patients with heart failure, Mitzi Saunders found that when tele management was used "*caregivers demonstrated how they entered the data into the devices*" (Saunders, 2012, p. 87). This study depicts spouses as more involved in the remote patient monitoring set-up than the first mentioned study. Involvement of the spouses or family caregivers in the Remote Patient Monitoring set-up is also documented in a RCT-study by Keanaly et al., looking at telecare for Diabetes, Heart Failure or COPD and the effect on quality of life, hospital use and costs. Here the spouse are, for example, reported to conduct the registering of health data on the user into the device and the transmitting the information to the response centre (Kenealy et al., 2015, p. 16).

In a study examining the social practices of the work of telecare, Rogers et al. also found that within a telemonitoring service many caregivers, usually the spouse, are key contributors when using the telemonitoring equipment and also key in regard to knowledge about the telecare. The home telecare activities were also considered a team effort (Rogers, Kirk, Gately, May, & Finch, 2011, p. 1082). Furthermore, in a study looking at how telecare developments contributes to reshaping the place and experience of care, the authors point to the fact that when care is provided from a distance, the actual care-work and the

responsibilities are shifted downwards, from the doctor, to the nurses, on to the monitoring centre staff and the family caregivers or the patients (Milligan, Roberts, & Mort, 2011, p. 352)

The four latter studies portray different roles and responsibilities for the family caregivers than Bregendahl & Laustsen's study. These studies indicate a direct involvement by the spouses in central processes in the remote patient monitoring set-up, while Bregendahl and Laustsen's study describes a more peripheral role of the spouse in the monitoring processes.

If we look at the roles and responsibilities of the family caregivers in another type of welfare technology, GPS- localisation for persons with dementia, a study by Thygesen and Moser found that alongside providing positive impacts on the family caregiver, this form of welfare technology did indeed provide them with new tasks and responsibilities. (Thygesen & Moser, 2014).

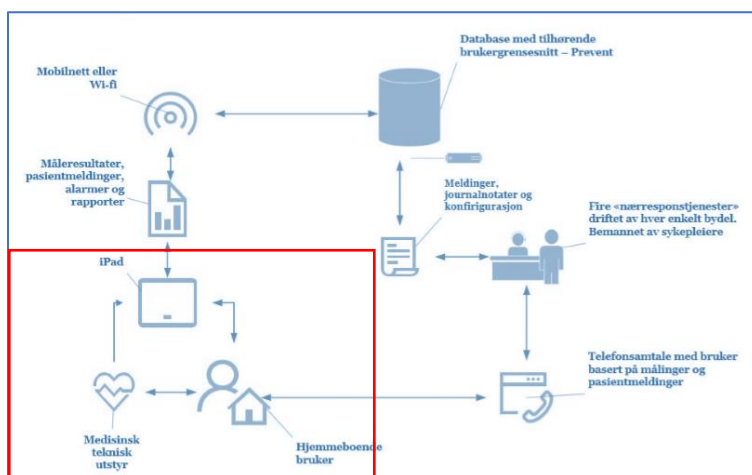
In a meta-ethnography of 15 research-papers reporting qualitative studies, it is found that digitally mediated patient – professional interactions, reconfigures social relations such as the family. The study describes how, in a telecare setting, the family members are at the very least required to contribute with co-presence and assistance if needed, and also that the relatives “can act as interpretive intermediaries shaping the space in which their sick relatives experience e-health systems” (Andreassen et al., 2018, p. 42).

Regarding the *competences* of family caregivers in a remote patient monitoring- setting, there is also a limited amount of literature addressing this specifically. Looking at the GPS- localisation study again, Thygesen and Moser found that many family caregivers “do not have the capacity, skills or competences needed in order to take on the new tasks and responsibilities by themselves” (Thygesen & Moser, 2014).

In a wider telecare context Milligan et. al also point to that both users of telecare and their family caregivers “may struggle to understand and engage with these systems” (Milligan et al., 2011, p. 353). A recent study by Karlsen et.al, looking at the use of telecare from the perspectives of older adult users and their family caregivers, portrays different levels of knowledge among the family caregivers in regard to the telecare devices.

Some had better knowledge than the home care nurses, others did not and expressed a lack of both information and training. (Karlsen et al., 2018, p. 9) On this basis, although there are differences in the findings, there are reasons to assume that the introduction of new welfare technology can challenge the competence of the family caregiver.

Remote patient monitoring in the context examined here consists both of iPad/tablet and different medical instruments and equipment suited for the need of the specific patient and their diagnosis, outlined in the picture below.



Source: (Intro International, 2018a)

When assessing the competence of the spouse in a Remote Patient Monitoring Context, it can be done both in regard to the use of the tablet and in regard to the medical instruments themselves. What does the literature say about the family carer competences in regard to the use of the tablets and the medical instruments?

A study on elderly persons and competence regarding the use of digital communication tools, such as tablets, found that there is an increase in elderly mastering both mobile phones and tablets, and that that more elderly are using the technology in social relations. It was also found that there are still barriers preventing use due to feelings of digital incompetence with the elderly user, and also due to feelings of the technology providing cold and impersonal relations. (Johnsen, 2017, p. 49). On this basis, although there is an improvement in the mastering of tablets and mobiles, there might be issues of lack of competence in this regard in the remote patient monitoring service.

Looking at the competence in the use of the specific measuring instruments, a study aiming to describe the process of family caregivers' learning how to manage technical health procedures at home, finds that *“teaching and support by health professionals (predominantly nurses) was focussed on the initial phase, but caregivers' learning continued throughout and developed through their own experience and using additional sources”* (McDonald, McKinlay, Keeling, & Levack, 2016, p. 2173). This indicates that although there is an initial need for the family caregivers to be taught how to use the instruments, they do become

familiar with it at an early stage and are able to advance their own competence in the use of the technical health procedures. Of the 27 family caregivers interviewed in the study, only 2 persons were over the age of 65, hence the main finding in the study might not be fully applicable for depicting the experiences of the older spouses.

Although not directly relevant for the assessment of competence it is however interesting that same study also found the use of the medical instruments and measuring to be an emotional experience for the family carer, where they were 'nervous' or 'fearful', and having to apply coping strategies when performing the procedures, such as humour and "switching off emotions" (McDonald et al., 2016, pp. 2180 - 2182).

Research question 2: How does remote patient monitoring impact the care burden of the spouse?

Chronic illnesses and the effect they have on the patients, both in regard to symptoms and mood as well as need for emotional and physical support, apply a burden on family caregivers (Goldberg & Rickler, 2011, p. 41). Specifically, spouses who are caregivers seem to have a tendency to believe that they "out of some sense of duty and fidelity" must be available at all times. (Kelly, 2010, p. 18). In their article "The Role of the Family Caregivers for people with Chronic Illnesses" Goldberg and Rickler argues that increasing burdens of care is one of the main consequences for family caregivers who are caring for the chronically ill. They further claim that this burden may lead to the caregiver postponing his or her own needs. In turn this may negatively affect a number of aspects of the caregivers life relevant for well-being (Goldberg & Rickler, 2011, p. 41). Care burden is defined by Lubkin and Larsen as: "the oppressive or worrisome load born by people providing direct care for the chronically ill, and that burden is relative to the level of the recipients disability, including behavioural issues, the extent of care required, and the caregivers level of worry of feelings of being overwhelmed" (Lubkin & Larsen, 2013, p. 256).

As mentioned above, care burden is one of the main consequences for family caregivers who are caring for the chronically ill and this burden has the potential to negatively impact other aspects of the caregiver's life. Therefore, examining how the spouses' care burden is impacted when their chronically ill partner receives remote patient monitoring, is an important aspect to include in this study.

Different tools have been developed for measuring the care burden of family caregivers. Two of these are the “Caregiver Strain Index” (Sullivan, 2002) and the “Care burden inventory” (Novak, 1989). The first mentioned index has five main domains of assessment of strain; Employment, Financial, Physical, Social and Time. Novak’s “Care Burden Inventory” consists of also of five main domains, namely the Time burden, Developmental Burden, Physical burden, Social Burden and Emotional Burden.

What does the existing literature state regarding the impact of remote patient monitoring on the care burden? There is one study that looks at the care burden dimension specifically, as one of in total three topics. In this quasi- experimental study of the effectiveness of telehealth concerning caregivers of health failure patients discharged from hospital, it was found that the degree of improvement on caregiver burden was significantly greater in a group receiving telehealth follow-up compared to the group that received conventional follow up (Chiang, Chen, Dai, & Ho, 2012, p. 1238). Care burden was in this study measured by a version of Novak’s “Care Burden Inventory”, mentioned above. According to the study, the care burden for the experimental group, when comparing pre-test and post-test scores, had improved greatly, and to a larger degree than the comparison group. The improvement on all of the burden dimensions were also significantly greater in the experimental group than in the group receiving traditional care (Chiang et al., 2012, p. 1237). This study indicates that an improvement in the scope of the caregiver burden for the caregiver can be seen after the introduction of a telehealth/remote patient monitoring service for heart failure patients. This study, however, only covers health failure patients, not the other diagnosis covered in Norwegian Remote Patient Monitoring, and the intervention is also applied for a shorter amount of time, in a more of a rehabilitation setting than in the Norwegian context.

In a recent study looking at the experiences of telecare among older adults and their family caregivers in a Norway, the positive effect on care burden is not so unequivocal. Here it is found that family caregivers may benefit from telecare, but also that it may add to their care burden, as the telecare service gave them additional responsibilities (Karlsen et al., 2018). As mentioned above, however, this study looks at a wider set of telecare services, not including remote patient monitoring as defined in this thesis, and only one of the family caregivers in the study, was an older spouse. Also in contrast to the findings of Chiang et al. is the study on GPS localisation and dementia by Thygesen and Moser, which argues that the new tasks and

necessary competences and skills can add to an already heavy care burden for many family caregivers (Thygesen & Moser, 2014).

Under the Norwegian Remote Patient Monitoring Project, final reports from some of the projects in the part-taking municipalities refer to observations regarding care burden for the family caregivers. Here it is claimed that some family caregivers experience that remote patient monitoring eases their everyday burden and that some find the remote patient monitoring service to be a relief (Dahl, 2018, p. 18; Garåsen & Kjeøy, 2018, p. 14).

Research question 3: What is the impact of Remote Patient Monitoring on the relationship between the spouses?

Being the caregiving spouse for one who is chronically ill may be a considerable task and can have significant consequences for the caregiver. In addition, the caregiving responsibilities can also have a major impact on the relationship between the spouse and the patient, a fact that should be a focus area for support efforts by the health care professionals, according to Lubkin and Larsen (Lubkin & Larsen, 2013, p. 257). Also the treatments for the diseases in themselves, given to the spouses for their chronic illness, can impact on the personal relationship, both regarding intimacy and effectiveness of communication (Kelly, 2010, p. 18). On this basis, it is relevant to examine if remote patient monitoring has impacted the relationship between the family carer and his or her spouse, and if so, in what sense.

In a study of “The Place of the Family in the Delivery of Telehealth” from 2013, the structured literature review found that little attention has been given to “*either the domestic relationship context in which such technologies are carried out or the impact of telemonitoring on existing relationships*” and that intimate others are viewed only as “caregivers” (Whitfield, Seymour, Plowman, & O’Leary, 2013).

Whitfield et al. claims that there are a limited number of studies addressing the impact remote patient monitoring has on the relationship between the caregiver and the ill spouse. This was confirmed by the literature review conducted in this study. However, two studies were identified that addresses impacts on the relationship as one of several topics analysed.

Looking only at one of the aspects from their study on the effectiveness of telehealth on family caregivers called “Family Functioning”, Chiang et.al finds that telehealth in the rehabilitation of heart failure patients had no significant effect on the relationships in the domestic sphere, both compared to the controlled group, but also when comparing pre – and post test results for the test group (Chiang et al., 2012, p. 1239). The fact that this study is conducted in a different cultural setting, where the dynamics in family relations might be different from Norwegian realities is an element to keep in mind, however.

Bregendahl and Laustsen, on the other hand, finds that the telemedical approach in rehabilitation of heart patients, has a positive effect on the relationship between the spouse and the patient. This is argued to happen because the telemonitored rehabilitation gave the couple a shared project and a new common interest. Telemonitoring provided the spouse with an active role in the rehabilitation which was found to be meaningful.

This common interest might however be more related to the lifestyle changing part of the telemonitoring regime, rather than the telemonitoring itself. As previously mentioned, the spouses in this study were only to a limited degree involved in the technology and the measurements. Moreover, this study also pointed to a reduction in the level of conflict in the relationship, as the nurses were the ones who monitored the compliance to the regime, not the spouse (Bregendahl & Laustsen, 2016, p. 135).

In a qualitative study conducted as part of the research on the welfare technology project in Oslo (Velferdsteknologi i Sentrum), it was found that, when being part of a remote patient monitoring service, the users experienced the service to provide a common platform of communication with their relatives and ensured a common knowledge of the disease which was reflected in their dialogue (Intro International & Arkitektur-og designhøyskolen i Oslo, 2016, p. 37). This finding however also covers other family caregivers beyond their spouse or partner.

Research question 4: How does remote patient monitoring impact Quality of Life related aspects for the spouse?

The document analysis identified a number of relevant aspects to discuss when examining possible impacts on the spouse. Many of these aspects arguably impact the spouses' quality of life. The quality of life related aspects examined here are topics that emerged from the document analysis of this study. These aspects cover elements that were found relevant to examine on the basis of previous literature, as well as topics mentioned in government documents concerning welfare technology and remote patient monitoring.

The quality of life related aspects that will be examined under this research question are mastery and security, worry and concern, as well as freedom and social and physical activity.

WHO defines Quality of Life as:

“an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.” (World Health Organisation, 2018).

In 2018 a report commissioned by the Norwegian Institute for Public Health and the Directorate for Health, “Guidelines for measuring quality of life in Norway” was published in an effort to provide a uniform and comprehensive approach in how quality of life should be measured (Nes, Hansen, & Barstad, 2018). The report provides a system for measuring quality of life, as well as recommendations concerning questions and methods suitable for use when conducting quality of life measurements in Norway.

The report builds on the view that quality of life is a complex phenomenon with both subjective and objective aspects. Subjective quality of life is about how life is experienced for the individual. It includes both assessments of life and daily functioning as well as positive and negative emotions. The objective quality of life is independent of subjective experiences, and aspects such as freedom, security, health, fellowship and self-development are core elements in the objective quality of life. (Nes et al., 2018, p. 9)

In the following section the different aspects relevant for examination under this research question will be more closely defined, and their relevance in regard to quality of life will be described using the guideline outlined above, and finally the main literature for the different aspects will be presented.

Mastery and security

Increased security and mastery of their own situation are two of the main goals for the user/recipient of welfare technology in general and remote patient monitoring specifically. In the definition of welfare technology used by the influential Hagen-commission, it is stated that it is:

“(...)technological assistance that contributes to increased safety and security, social participation, mobility and physical and cultural activity, and supports the individuals ability to manage everyday life, regardless of illness and reduced social, physical and mental ability” (NOU 2011: 11, 2011).

The emphasis on security and mastery can also be seen in the government initiated research on the Remote Patient Monitoring project, where a main research question is *“to what degree does remote patient monitoring lead to increased mastery and security among the users?”* (Intro International, 2018a, p. 7).

Similar improvements on the side of family carers are also sought when implementing welfare technology in the Norwegian context and is stated in various documents and reports. In the already mentioned definition of welfare technology (NOU 2011: 11, 2011) it is said that *“(...)welfare technology can also serve as support for relatives...”*.

Furthermore, in the final report on the Remote Monitoring Project in Oslo it is specifically stated as one of the main overall goals in the testing of welfare technology that: *“(...)users and relatives experience increased security, mastery and independence in their own home”* (VIS- Velferdsteknologi i Sentrum, 2018 p. 5). Increased security for the relatives is also a separately stated goal in the same project (VIS- Velferdsteknologi i Sentrum, 2018 p. 17).

Mastery can be defined as “ ..the extent to which one believes that one's life experiences are under one's personal control” (Bookwala & Schulz, 1998) or a set of skills which allows people to exert assertion and constructive control over their environment (Nugent, 2019a). The concept of mastery is an important element in the subjective quality of life, that is of how life is perceived to be by the individual and in the persons perception of daily functioning (Nes et al., 2018, p. 9). In the recommended guidelines for measuring quality of life in

Norway, “Mastery” is a part of the main list for measuring subjective quality of life and is measured through five questions, covering mastery and control in everyday life (Nes et al., 2018, p. 29).

Looking more specifically at mastery and caregivers, Lubkin and Larsen states that caregivers who have a “higher sense of self-efficacy and control over their life situation, i.e. personal mastery, have less burden and fewer depressive symptoms” and goes on to say that “studies suggest that interventions that enhance self- efficacy or personal mastery will decrease health risks and improve health related outcomes for caregivers. “ (Lubkin & Larsen, 2013, p. 257).

Knowledge of their partners condition and understanding of symptoms is an important aspect of mastery and control over the life situation for the family caregivers, and sufficient knowledge on symptoms is an important element for a family caregiver’s confidence in the caregiving context (Andersen, Strøm, Korneliussen, & Fagermoen, 2016). According to Lendrum & Syme, the loss of ability to plan is also a key challenge for a family caregiver (Kelly, 2010; Lendrum & Syme, 2004). When examining the user-experience among the users of Remote Patient Monitoring in the research on the National Remote Patient Monitoring Project, the ability to conduct everyday planning was one of six questions that the users were asked. (Intro International, 2018a). As seen above, control in everyday life is also an important aspect of mastery (Nes et al., 2018, p. 29).

On the basis of the stated policy goals of increased mastery and independence for the family caregivers through Remote Patient Monitoring initiatives, as well as the high relevance of mastery for quality of life, examination of how Remote Patient Monitoring impacts on the mastery of the spouse is of interest in this study. Based on the definition of mastery, related topics in the literature, definitions of welfare technology and outcomes sought for the family caregivers in the welfare technological context, mastery will in this study be defined as control and knowledge in relations to the condition of the spouse, their feelings of independence and perceived ability to plan in their everyday life.

What does the literature tell us about how Remote Patient Monitoring impacts on the mastery of the spouse? Two studies have been identified that address this issue. As mentioned, mastery can be understood to be the extent to which one believes that one's life experiences are under one's own personal control. In a study conducted in New Zealand on telecare for people with diabetes, heart failure and COPD, one of the key findings, regarding the family caregivers, was that telecare had taught the family caregivers more about managing their partners condition and led to them taking a more active role in self-management. (Kenealy et

al., 2015, p. 2). In the study by Thygesen and Moser on GPS localisation and family caregivers, it is found that this form of welfare technology can increase independence of the family caregiver (Thygesen & Moser, 2014).

Security. As shown in the beginning of this section, security is seen as one of the main goals for both users/recipients and their family caregivers in the context of remote patient monitoring. In the literature regarding remote patient monitoring and security, the concepts of both security and safety are stated as desired outcomes for the spouse when introducing welfare technology. So before looking at the previous academic work on this topic, it is necessary to address the definitions of these two concepts.

Security can be defined as being “the state of feeling safe, stable and free from fear or anxiety” (Oxford Dictionaries, 2019), or more detailed as: “An experienced, significantly subjective feeling of physical predictability in the environment, which includes physical, mental and social conditions associated with the individual and the society, including belonging, mastery, and quality of life.”(Skadeforebyggende forum, 2019). Safety can be defined as “the condition of being protected from or unlikely to cause danger, risk, or injury” (Oxford Dictionaries, 2019), or more detailed as “a condition characterized by a fairly high degree of control over physical, material or psychosocial threats that create an experience of protection and reduced danger of unwanted events”(Skadeforebyggende forum, 2019).

In a study aiming to understand the concept of safety in the context of home-delivered health care from the perspective of key stakeholders, safety is by the patients and their caregivers defined as:

“the meeting of complex care needs to generate positive clinical, physical, psychological and social outcomes and the reduction of risk of negative outcomes. Patient and carer can actively participate in efforts to be safe in addition to health care provider contributions” (Jones, 2016, p. 2542).

Security is among the core elements within the objective quality of life (Nes et al., 2018, p. 14). Security covers in this context many different aspects of security including physical safety, job security and safety in the community, but also “security related to receiving the help you need in different situations, for example in case of illness or injury” (Nes et al., 2018, p. 17). This study will apply a wide approach towards the definition of security, aiming to capture the spouses’ perception of security in the context of remote patient monitoring.

In a study looking at family caregivers of heart failure patients receiving home care nursing, all of the five families that received additional tele management support, found it to make them feel more secure. The author also emphasizes this finding with a quote from one of the caregivers, describing a feeling of comfort in the fact that the nurses are monitoring the patient and will make contact on the tele management device and give instructions on what to do (Saunders, 2012, p. 86). In Bregendahl and Laustsen's study it is also found that the telemedical rehabilitation scheme creates a feeling of security for the family caregivers in their everyday life, and that this feeling is largely connected to the nurses' remote monitoring of the patient (Bregendahl & Laustsen, 2016, p. 138).

Chiang et al. also points to findings of increased certainty among the family caregivers. According to this study, knowledge and information about their partner's condition and measurements is a main factor of increased certainty. However, this study also found that this certainty is related to contact with nurses: "Daily communication with the telenursing specialist reduced their uncertainty, especially since they could frequently and quickly receive help and information from the physicians", (Chiang et al., 2012, p. 1239). In a study examining telenursing within home healthcare of leg wounds and patients and to some extent next-of-kin in collaboration with nurses, it was found that being able communicate with nurses via videophone and seeing another human face gave a sense of security, which was explained to have a calming effect (Jönsson & Willman, 2008)

Impacts on family caregivers in relation to security is also addressed in various project reports in the Norwegian Remote Patient Monitoring Project. Three of these report on findings of family caregivers experiencing increased security when their family member receives remote patient monitoring services (Dahl, 2018, p. 18; Garåsen & Kjeøy, 2018, p. 14; Intro International & Arkitektur-og designhøyskolen i Oslo, 2016, p. 32).

Worry and concern

Although being the family carer for a spouse may also provide intrinsic awards for the caregiver (Baanders & Heijmans, 2007), the literature also points to more challenging consequences, such as emotional strain, anxiety and guilt, depression, fatigue and emotional stress (Kelly, 2010; Lubkin & Larsen, 2013; Saunders, 2012). In the literature on remote patient monitoring the topics of worry and concern is specifically addressed and these factors will also be discussed in this study.

Worry can be defined as “a state of cognitive distress or worry because of concern over an impending or expected occurrence, risk, or threat” (Nugent, 2019b). Worry is also an element in the measurement of the subjective quality of life, more precisely under the affective quality of life measurement (Nes et al., 2018, p. 26). Aspects of worry are also assessed as part of the objective quality of life and living conditions measurement (Nes et al., 2018, p. 31)

Bergendahl and Laustsen argues that the family caregivers affected by telemedical rehabilitation and remote monitoring by nurses, experience a reduction in the level of worry in their everyday life. They also found that this is due to the nurses’ support and control through the telemedical equipment. The caregivers also find it a relief to not have to worry about their spouse complying to the rehabilitation scheme, as this is covered by the nurses’ monitoring. (Bregendahl & Laustsen, 2016, p. 138 & 139).

In Karlsen et al ’s study of experiences among older adults and caregivers receiving telecare services (not including remote patient monitoring), the family caregivers did in fact, after a period of feeling ease, report of stress and concern regarding the telecare service. Their worries, however, were not directly connected to the telecare service itself, but to the telecare service’s facilitation of the older adult user’s desire to live longer at home (Karlsen et al., 2018, p. 1).

Freedom and social and physical activity

In the literature on being a family carer for a chronically ill spouse, studies show that the condition of the partner can have consequences for the spouse, such as setting aside their own needs, hindering personal achievements, disrupt social relations and restrict flexibility in their personal life (Baanders & Heijmans, 2007, p. 306 & 308). Other consequences mentioned are tendencies to overlook their own personal health needs, lack of physical activity and little time for themselves (Saunders, 2012, p. 86 & 87).

In this study, I have chosen to examine if the spouses experience a change in their ability to have time for themselves and be physically and socially active due to remote patient monitoring. Aspects related to social and physical activity are both elements in the previously mentioned quality of life measurement guidelines, and are both categorized under the objective quality of life measurement (Nes et al., 2018, p. 34 & 36). Furthermore, aspects related to social support and affiliation/belonging, social fellowship and friendship are also part of the subjective quality of life measurements (Nes et al., 2018, p. 27).

Bregendahl & Laustsen found in that the family caregivers have more time for themselves due to the flexibility of the monitoring and the telemedical rehabilitation set up. They also found that the family caregivers achieve more freedom when their partner, through the telemedical rehabilitation services, is more active in their own treatment (Bregendahl & Laustsen, 2016, p. 134 &140).

Looking at other forms of welfare technology, Karlsen et al.'s study points to a finding where one of the older spousal caregivers felt less homebound as the telecare service - medicine dispensers - had made them less dependent on home care services (Karlsen et al., 2018, p. 9) and Thygesen and Moser also point to impacts such as increased independence and possibility of living a more active life for the family caregiver resulting from the welfare technology GPS-localisation (Thygesen & Moser, 2014, p. 15).

Chapter 4 - Results and findings

This chapter is organised according to thematical framework and the findings for each of the four research questions will be presented (one at a time), and the findings will be compared to the previous scholarly contributions and literature that were outlined in the previous chapter.

Research question 1: What are the roles and the responsibilities of the spouse in Remote Patient Monitoring and do they have the needed competence?

The Role of the Spouse

When investigating the role of the older spouses in the data a distinction between roles at different stages emerged. There seems to be one type of role-profile for the older spouses at the introduction and entry point into the service, and another role-profile in the operational phase.

An Initial Joint Venture. At the very start of the service and also when introduced to the service, there seems to be a distinct “we-mode” in the eyes of the spouse. Here the spouse and the user/recipient are introduced to and enter this service as a unit and appear to be equal partners. Four of the five spouses, regardless of their role and level of involvement at a later stage, clearly depicts a unit-orientated entry. This can be exemplified with the following quotes:

Informant 1: “...**We** were at [the hospital] when a nurse or something came in and started talking about this and she had brought with her some brochures for **us** explaining what this was. And I thought, “this sounds really good” (...) And then I thought that this is something **we** must apply for. So, **we** did »

Informant 2: “...**we** were asked if **we** wanted to take part in this project, and **we** said yes – to see what it was”.

Informant 4: «...it was a question from the people at the care centre, where the response centre is, [...] if this was something **we** could consider taking part of, and **we** agreed to do take part [...]”

Informant 5: “... It came from of nowhere, **we** were told that **we** could receive this kind of equipment, and **we** thought that it was absolutely fine.”

The study also finds that, at entry point, all the spouses have a positive attitude towards the service. This positiveness appears to be related to a perception or feeling that entering this form of service is a rational choice to make. That the Remote Patient Monitoring service is seen as a reasonable service to pursue or to try in their situation. When asked about their initial thoughts about the service and their answers have a similar rational voice;

“It sounded very all right”

“I found it to be a sensible arrangement”

“If this could help her at all, I thought it to be absolutely fine”

“...we thought it sounded very all right”.

One informant however, also added another motivation factor at entry point that is less based on rationality than described above. This spouse also mentions the service as being “new and a bit exiting” as a motivation. This motivation based on excitement might be more of an expected motivation in a new technology context. Here however, rationality seems the main driver.

In the second report from the research on the Norwegian Remote Patient Monitoring Project it is, based on findings in Kapadia et al., Chatwin et al. and Kenealy et al., highlighted that “the family caregivers impact on the accept of the technology appears to be large”, and that “family has an important support-function in the users accept of the technology” (Intro International, 2018a, p. 68).

In the study by Karlsen et al. family caregivers were also found to be “driving forces behind the telecare service” and had themselves initiated services or arranged for telecare devices. (Karlsen et al., 2018). The findings in this study also indicate that the older spouses might play important roles in a sustainable entry into the service, as they appear to have a large and equal role at introduction and entry point. The rationality and positiveness in the support of the service can also be seen as an indication of the same.

Variation in the roles at the operational stage. When looking at the role and involvement of the spouse at a next stage and when the service is in operation, there appears to have been a shift in the role-profile from the initial phase.

The reasons for this shift have not been the subject of investigation, but one factor that might provide one perspective is described by one of the Health Care professionals:

“In the very beginning I think that they do it together, because they are a bit uncertain. One of the new patients had never seen or owned a smartphone or tablet before – and [the spouse] helped in the very beginning – but now the patient manages things by [him/her self]”.

Another perspective on the shift might be the entry of normality, and, or an adjustment to already existing relationship dynamics.

In the operational stage, the qualitative interviews show that the roles of the spouses diverge. This is also in line with the impressions of the Health care professionals in the study’s second sample, describing a large degree of variation in the roles of the spouses they have interacted with. This is also the case for the five spouses interviewed in this study.

Based on the view they have of their own involvement, they represent different types of roles and levels of involvement. On one side there are those that describe their role as both large and critical to the sustainability of the service. When asked if their role in and presence in the Remote Patient Monitoring-processes are important, one spouse replied:

“Oh, yes, absolutely (...) this isn’t something [spouse] could manage alone”.

On the same question, another replied:

“Yes, I would say that it is crucial, and then everything happens by itself...”.

On the other hand, others portray their involvement as marginal to none, or say that their involvement is on an ad-hoc basis. For example, when asked:

“Do you consider that you are an important piece of the puzzle in the processes in the service?”,

one spouse replied:

“No, not really, but I will assist of course if there is a need – but this is something [spouse] handles by [her/him] self”.

Another informant replied, when asked if he considered his role and participation in the service to be large:

“No, this is something she fixed all by herself”.

As seen, previous literature concluded differently when it comes to the spouses' or family caregivers' role and involvement in the Remote Patient Monitoring processes. According to Bregendahl and Laustsen, the spouses surveyed in their study were to a limited degree involved in the processes and use of the telemedical equipment (Bregendahl & Laustsen, 2016, p. 140). This is partially supported by findings in this study, as three of the spouses perceive their role and involvement as limited to none.

However, the role and involvement of the two other spouses in this study represent an opposite finding. Both of these two informants are heavily involved in the processes and set-up of the Remote Patient Monitoring. This is more aligned with the conclusions of Rogers et al., who claim that family caregivers are key in regard to knowledge about the telecare, and argue that the home-based telecare activities are considered a team effort (Rogers et al., 2011, p. 1082). The findings in this study, however, also go beyond Rogers et al. as the spouses in question in some ways can be said to be a main operator of the Remote Patient Monitoring set-up in the domestic sphere.

A wide range of responsibilities. This study has identified a range of possible tasks and responsibilities that might be acquired by the spouse as a part of the Remote Patient Monitoring service and its' set up. This is aligned with findings from the study of GPS localisation and family caregivers, by Thygesen and Moser (2014), in which the family caregivers were found to receive new tasks and responsibilities as a result of the introduction of the welfare technology.

The tasks and responsibilities the spouses have acquired are both large and small and cover many different sub-processes of the Remote Patient Monitoring service in the domestic sphere. Some of the tasks and responsibilities identified are addressed in the previous literature and some tasks and responsibilities are not. As shown above, the spouses represented different role-profiles and in the cases where the spouses have large roles in the service, they are also responsible for a large number of tasks. Those who stated that they have a smaller or marginal role have a limited number of tasks.

The list of tasks and responsibilities identified here, is most likely not exhaustive as to potential efforts of the spouse. Still, it can provide an overview of the range of possible tasks that a spouse may acquire and illustrate the variety of responsibilities for this group.

The tasks and responsibilities will in the following be presented, exemplified with quotes from the data material along with a description of the scope of both the responsibilities and the tasks. In addition, the findings of the study will be discussed with reference to the conclusions of previous studies in cases where relevant literature was identified in the systematic literature review (see Chapter 3).

1. Medical instruments operation

This specific task is related to measurements of the health parameters of the patients. Findings in this study show this to be the case on a regular basis and a main responsibility for two of the informants and on more of an ad hoc basis for one informant. Four of the five informants had to some extent used the medical equipment and conducted measurement of health parameters.

One of the informants describes his or her medical responsibilities in the following manner:

Informant: *“We measure blood pressure, pulse and oxygen saturation, that’s what we were told to do”*. Interviewer: *“...and you are the one responsible for conducting the measurements?”* Informant: *“Yes, I am”*.

Another informant responds in this way, when asked if he or she participates in the measurements:

“Oh, yes – I am the one managing all that, [spouse] is not that interested – I’m sure [spouse] could manage, it’s not that, but [spouse] just sits there beside me you know – and it all works just fine”

The involvement in this form of task or activity by the spouse or family caregivers is addressed in a study conducted by Milligan et.al, and findings include that in a telecare context, care-work and responsibilities might be shifted downwards, from the doctor, via the nurses and on to the monitoring centre staff and the family caregivers or the patients (Milligan et al., 2011, p. 352). Findings in this study support this, as two of the informants on a regular basis are responsible for use of the medical equipment and measurement of health data, and a third informant is responsible on an ad hoc basis. The two other informants, however, differ from the pattern identified by Milligan et al., as they do not have this kind of responsibility.

2. Registration and transmitting of data

This task is in a way a prolongment of the above-mentioned task, most of the production and transmitting of data occurs automatically, but there are some manual processes. Findings in this study include activities on the side of the spouse such as reporting the patients self-reported health data into devices, in cooperation with the patient, and transmitting the information to the response centre. This is however only the case for one of five informants in this study, however, similar tasks and activities on the side of the spouse found for the one informant are also found in previous literature in studies by both Saunders and Kenealy (Saunders, 2012, p. 87) (Kenealy et al., 2015, p. 16).

3. IT and Operational Support

Identified responsibilities held by the spouse also cover activities associated with IT and operational support functions and include the following:

Making sure that batteries on equipment are changed:

Informant: *“...there was one day when I thought, what in the world has happened...because no one has told me I had to change the batteries... but I found out”.*

Securing that the tablet is charged enough:

Informant: *“I just have to make sure that the tablet is charged sufficiently and has enough percent, then it’s just to connect and you are on your way”*

Supports and assists in the use when the equipment has started to wear and does not work as well as in the beginning.

Informant: *“Well, you see, that computer has been a bit difficult lately (...) It has a tendency to discharge faster than before, to put it like that (...) so I have had to take part in quite a lot lately”.*

There is no literature addressing challenges or responsibilities in relation to information technology support or securing battery function and charging routines on the side of the family carer within the context of Remote Patient Monitoring.

In the context of GPS-localisation these issues; responsibilities concerning charging of the technology units and securing its battery function, are specifically addressed in the literature. In a study by SINTEF (“Safe tracks”/Trygge Spor), which has been an important contribution

to the development of the GPS – localisation services in Norwegian municipalities, charging of the GPS-unit is highlighted as a technological and organisational challenge.

As I have shown in my own study, it was also found in the SINTEF study that the charging of the technology units was the responsibility of the family caregiver in some cases (Ausen, 2013, p. 48). The responsibility of securing a sufficiently charged technology unit is however arguably of more importance within GPS – localisation technology.

4. Just being a companion...

Being present at meetings or providing support in certain situations are also responsibilities or tasks as described by the spouses. Below I illustrate this with some examples from the interviews, including this one:

Informant: *“[Spouse] is quite capable of taking care of all those things alone, so I am not a driving force or anything (...) but of course I give my support when needed”.*

When asked if he/she took part in meetings with health care personnel as part of the Remote Patient Monitoring service another informant replied that he/she did:

“I go along to the meetings, and the last few times he/she has gone to the doctor I also went along, it’s what he/she wants, so...”.

Activities related to this category of responsibilities are along the lines of the findings in a review-study by Andreassen et al., where it is highlighted that family members in a telecare context are at least required to “contribute with co-presence and assist if needed”, and can act as “interpretive intermediaries shaping the space in which their sick relatives experience e-health systems” (Andreassen et al., 2018, p. 42).

5. Assisting administratively

The study also identified more administrative tasks on the part of the spouse. Findings show that tasks such as making sure there are reminders set in calendars to make sure that the patients’ regular appointments are met, and required tasks conducted, are responsibilities that can be held by spouse. This administrative task is explicitly mentioned by two of the informants.

Informant: *“Well, I manage to set a reminder, that repeats weekly, when [spouse] has the calls with the response centre, in order to remind [spouse] to turn on the tablet”.*

Another informant explained:

“Well, we had some trouble forgetting at first, so I just set an alarm on the phone, and now it works fine. (...) it’s better to have it on my phone because I never put it away, regardless of where I am”.

This study has not found this particular task addressed specifically in previous studies. The task can at first glance seem a trivial one, and even minuscule, however securing compliance to the regularity of the service can also be argued to be a central task to the Remote Patient Monitoring set-up.

6. Communication responsibilities

Responsibilities related to contact with the health care personnel and/or response centre also emerged from the data, revealing several different possible tasks.

For example, in one of the cases the telephone that was used as the point of contact between the patient and the response centre was in fact the spouse’s telephone and telephone number. In another example provided by the health care personnel, a spouse had also been responsible for the regular conversations with the response centre on behalf of the patient. Another task identified under this heading is the responsibility for notifying the response centre if there is a planned deviation from to the original set up of the service, for example due to absence from the home:

Informant: *“I call them and tell them that there will be a break, so that they don’t wonder”.*

7. Hospitality and human relations

One last task identified on the side of the spouse are activities that seems to be conducted to establish and/or maintain a good and positive relationship with health care personnel in the remote patient monitoring service. As explained by one of the spouses, [he/she] takes an active role in building positive relation between the patient and the response centre personnel. The informant makes sure that the health care personnel are offered a cup of coffee when they make house visits to their home. It is also highlighted that [he/she] is mindful to praise them for their work when they are present in the home, as this is perceived to be appreciated by the health care personnel.

Previous studies find there are a variety of different roles and responsibilities performed by the spouses in Remote Patient Monitoring. In some studies, a limited role of the spouses in the telemedical processes is portrayed, in other studies more extensive roles and various activities are described. As illustrated above, this study has identified a large number of possible tasks and responsibilities the older spouse could acquire in Remote Patient Monitoring and may therefore be argued to support the latter perspective. However, there are large individual differences among the surveyed couples, in terms of both the size of the role and the type and number of responsibilities the spouse has. There are those that are heavily involved and there are those that to a limited degree are involved, supporting the first mentioned perspective.

To which degree the role or involvement of older spouse, through the different tasks performed, represents a critical effort for the sustainability of the remote patient monitoring is not possible to evaluate from this study and has not been its ambition. However, it is notable that tasks, small or large, that have a potential to be important to the sustainability of the service, are acquired by the older spouse in some cases.

This finding is relevant also in light of the fact that it seems that the role of the spouse develops informally in the domestic sphere and adjusts to individual domestic dynamics. None of the informants, report having formally been provided with roles or responsibilities within the service. This also seems to be the case when the older spouses have large roles in the remote patient monitoring. Based on information acquired from the health care professionals interviewed in this study, providing spouses with formal roles within Remote Patient Monitoring is not common practice.

Three findings from this study should be highlighted in regard to the roles and responsibilities of the spouse. The first is the range of possible responsibilities that the spouse can acquire, some of which not addressed in previous literature. Secondly, the processes of distribution and acquirement of tasks seem to materialize in the informal domestic sphere, rather than in a formal one. Thirdly, spouses who have little or no perceived involvement, may still acquire important tasks. Furthermore, these responsibilities may potentially be central tasks to the sustainability of the Remote Patient Monitoring. To mention one example: one of the spouses interviewed in this study perceives himself/herself to have no role and involvement at all. Nonetheless, the informant in fact secures the weekly appointment the spouse has with the response centre by having a calendar reminder on his/her own mobile telephone.

Competence

Simplicity and easy use. The spouses that are involved in the processes in the Remote Patient Monitoring service portray the Remote Patient Monitoring technology as easy to use. When asked if there are any challenges or difficulties in the use of the technology and the instruments, one informant replies:

“...the specific operations are very easy”.

Another replies:

“...it’s very easy”.

Also, one of the informants which is not involved in the processes has a clear impression of simplicity:

“[spouse] has a thing and puts it on the finger to measure saturation and pulse and it uses Bluetooth over to the tablet – and it pops up – and I think that [spouse] just presses a button and it’s sent”.

From the viewpoint of the health care personnel it is also argued that the technology and instruments in the Remote Patient Monitoring service are easy to use, both for the patient and the older spouses which take part and emphasize that simplicity is a crucial factor when introducing technology in health care, and especially among older people.

Training. This section focuses on training provided for the spouses regarding the use of the tablet and the measuring instruments. The main impression of the health care professionals surveyed in this study is that the training in the use of the technology is mainly provided to the user/recipient. They also report that training of the spouse depends on their own interest and whether or not they are present when the user/recipient receives training.

Among the older spouses surveyed in this study, two of the informants have not been given any training at all, these are also the ones that have limited overall involvement. Training activities is however sought by one of these informants. The two other spouses, who have a larger involvement, report having received training by the health care personnel in their own home, and one had also been given additional written information.

One of the health care personnel informants comments on the relevance of the spouses' participation in the training:

“The last few (spouses) have joined (the training) and watched, and it's better that there are four eyes watching, and not only two – right? Then they remember more the next time”.

Prior knowledge, but also hesitations towards “the computer-stuff”. Although the main impression is that there is a perceived simplicity and ease in the use of this welfare technology, there are a few signs of hesitation and challenges. In the previous section possible challenges in regard to competence were addressed in relation to the use of the tablet on one side and in relation to the use of the medical instruments on the other side.

Among the spouses, there were no hesitations or reluctances noted in regard to the use of the medical equipment, this was featured and also seemed to be handled in a natural and automatic manner, without any qualms. This is in line with the findings in McDonald et al.'s study (2016), describing independence and development of familiarity on the side of the family caregiver at an early stage, after initial training.

One informant describes it this way when asked if there are any challenges related to the use of medical instruments:

“No, I don't find that at all, because when [spouse] does the blood pressure, it's just done in the same way the doctor does it – you put a thing around your arm and pump it up and read the results – and there is one thing to blow in and another widget to put on the finger (...) It's easy stuff.

The signs of hesitations are expressed in relation to use of the tablet. In the case of one of the spouses, even though describing both prior computer and data competence, as well as prior experience with tablets, reluctance towards the tablet appears to be a reason for the spouse to distance him/herself from the processes;

“No, this is something [spouse] fixes by [her/him] self. [She/he] is much better on the computer than me (...). As I say, I'm not very good with this computer stuff, I have a tablet and all and use it a bit, and I also used to work with computers as a tool at work, but I have never really liked it much”.

Another informant, also one of the two who play a relatively small role within the Remote Patient Monitoring service, also has a negative view of the tablet and portrays it as a “quarrelsome” and “difficult” computer on account of its increased level of discharging.

One of the health care professionals also mentioned that some spouses show reluctance towards using the tablet. According to this informant, the degree of reluctance depends on the spouses’ and users’ level of prior experience with the use of smart phones and tablets.

The two spouses that are more heavily involved in the processes, both explain that they have prior competence with relevance to the use of the tablet and voiced no hesitations to the use of it under Remote Patient Monitoring. One report of having experience with the use of computers, however not with tablets specifically and was therefore first introduced to this by the health care personnel when the service was implemented. The other informant had prior experiences with Ipads and also found the tablet to be easy to use in the Remote Patient Monitoring context.

The literature on competence among older people in the use of digital communication, such as tablets, states that there is an increase in this group ‘s mastering of tablets. However, it is also argued that there are still barriers to usage caused by feelings of digital incompetence amongst some elderly people (Johnsen, 2017). Both of these conclusions may be argued to be supported by this study. However, the hesitations and reluctances uncovered in this study seem to be a reason for the spouses to distance themselves from the process, rather than partaking in them with a feeling of inadequacy.

Research question 2: How does remote patient monitoring impact the care burden of the spouse?

Caregiver burden can be defined as: “the oppressive or worrisome load born by people providing direct care for the chronically ill” (Lubkin & Larsen, 2013, p. 256) and this research question seeks to uncover if the care burden the older spouse experience in relation to their spouse’s illness, is in some way impacted by the remote patient monitoring service. Findings related to this research question will be presented in the following sections.

It is not so much the time or the scope...

In this study, all but one of the spouses in this study experienced a change in their care burden and the main impression is that the informants' care burden was reduced because of Remote Patient Monitoring. This is in line with the findings in Chiang et al.'s study on the effectiveness of telehealth on family caregivers, where the care burden score saw an overall improvement for the experimental group after the telehealth intervention, significantly greater than for the comparison group (Chiang et al., 2012).

The informants in this study were asked if the scope of their care burden and time used had changed as a result of the remote patient monitoring. Their answers leave the impression that the spouses do not experience a change in the scope of their caregiving or time used as a result of the remote patient monitoring. When asked about the extent of their care activities and time used their replies are quite similar:

"Well, it's more or less the same"

"No, I can't see that it has changed, it's more or less the same"

"No, I really think it's the same. There is no difference at all".

The reduction in care burden for the family caregivers in Chiang et al.'s study, after the introduction of the telecare intervention, was due to an even distribution among all of the sub-dimensions in Novak's "Care Burden Inventory"; Time burden, Developmental Burden, Psychological burden, Social Burden and Emotional Burden. Although the analysis of care burdens in this study is not directly comparable to the dimensions used in Chiang et al.'s study, it is worth noting that the dimension of time burden does not seem to be impacted in this study. All the informants reported that the time used for care and the scope of their care burden had not changed as a result of remote distance monitoring, and this differs from Chiang et al. who find that time burden was improved along with the other dimensions.

Also, the fact that none of the spouses described a negative effect on their care burden can be viewed to be notable, particularly since the spouses have actually acquired new tasks as a result of the remote patient monitoring service, albeit of varying character and scope. When asked about changes in their care burden, acquisition of the new tasks is not, in the context of care burden, associated with an increase in the burden. When talking about their care burden, the acquisition of new tasks due to Remote Patient Monitoring is commented on specifically by two of the informants. However, in this context the tasks are not portrayed by these informants as negatively affecting their care burden.

Previous literature on other kinds of welfare technologies have pointed to that implementation of these technologies can result in additional responsibilities for family caregivers and that these responsibilities may add to the family caregivers care burden (Karlsen et al., 2018; Thygesen & Moser, 2014). As shown above, all the informants in this study have to some degree acquired new responsibilities under the Remote Patient Monitoring service. In this study, however, the informants do not express that their new tasks under Remote Patient Monitoring adds negatively to their care burden, in contrast with other studies.

... it is the sharing of responsibility that takes a load off.

Three factors leading to an experienced reduction of care burden for the spouses emerged from the qualitative interviews in this study.

Sharing of responsibility. The most prominent factor is the experience of sharing responsibility for their ill partner with somebody. The spouses seem to find relief that they under the remote patient monitoring no longer have the feeling of being alone with the responsibility. One of the informants explains this sentiment in the following manner:

” I would say that the responsibility has lessened – because it is a bit divided now, right? – when we send this in every day I feel that the responsibility has become less – it’s sort of more people involved and it is shared in a way” (...) “ ..When we have sort of sent the data on, it gets easier in a way with the responsibility being shared”.

Another informant puts it the following way:

“...If there are any irregularities in the blood pressure they call at once, that is really nice – we have backing there and that feels good”.

A third informant explains that the burden is reduced because the responsibility is now shared with someone who also has an authority as a professional:

“I’m sure that if that nurse had said “now you have to go to see the doctor”, then [spouse] had been standing on the doctor’s doorstep the next day”

One of the informants in the studies second sample, the health care personnel, also emphasizes that Remote Patient Monitoring introduces a third party that may provide relief for the older spouse:

“I have seen some that are brought to tears, because now there are more people involved, and it is obvious that this is something that they have been carrying around by themselves for a long time and felt – well – they have been so so worried”

Access to health care personnel. A second factor found to reduce the care burden for the spouses is the improved access to health care personnel, and not having to seek consultation and wait for a doctor’s appointment to be a main relief here.

One informant explains:

” ...Now I don’t know longer have to think: “do I have to contact the general practitioner now?” and he is not there every day and we don’t have to take the trip down there. If I have a question, I just write it down and [nurse] answers at once”.

Another describes like this:

“... and [spouse] has someone to call (...). This is at least an easily accessible offer for advice and to have someone to ask if one is anxious and those kinds of things, and one can avoid having to see the doctor – and getting him on the phone is not possible(...) There has been quite a lot of emergency rooms and 113 and things like that”.

Knowledge and control. A third, but somewhat less prominent, factor that impacts the care burden positively for the spouses is the increased knowledge and control over the health situation of their partners, due to the technology and the measurements.

One informant explains:

“... It’s the worrying that’s become less (...) it helps me and gives me answers”

Another informant explains it like this, when describing increased experience of knowledge and control:

“Now we don’t have to go to the doctor to do the measurements, which we had to do before this, so that’s good...”.

The overall impression in this study is that the care burden, in the perspective of the older spouse, is reduced as a result of Remote Patient Monitoring. These findings support to a large degree the positive effect of Remote Patient Monitoring on the overall care burden of the family caregiver as described by Chiang et al. However, as previously mentioned, in Chiang et al.'s study the improvement in care burden were evenly distributed between the sub-dimensions, Time burden, Developmental Burden, Psychological burden, Social Burden and Emotional Burden. In this study the positive effect on care burden is not related to time or scope, but rather to factors relating more to the other sub-factors in the care burden inventory.

There might be several reasons behind this difference in regard to the time-dimension. It might be so because they have actually acquired new tasks, and this might cancel out any initial positive effect on their time burden. Another possible, and maybe more plausible explanation, might be that time is not such a scarce a resource for this age group, compared to younger age groups, and hence not as important a factor of improvement. In Chiang et al.'s study, half of the participants in the experimental group were below the age of 59, while the other half were above the age of 60.

Summing up, in this study the reduction of the care burden the informants experienced is mainly related to the Remote Patient Monitoring's introduction of a professional third party with whom the spouses feel that they can share the responsibility for their ill partner. Better access to health care professionals, and not having to wait to seek consultation with their doctor and general practitioner was another main aspect pointed to by the spouses interviewed to reduce their care burden. The informants also expressed that the increased knowledge and control they experienced as a result of Remote Patient Monitoring, improved their burden.

There has recently been published several concluding project reports in the municipalities that were part of the first Remote Patient Monitoring Project under the National Welfare Technology Program that ended in 2018. Some of these reports address and describe observed effects of remote patient monitoring on family caregivers. These reports highlight that family caregivers experience that remote patient monitoring eases their everyday burden and is found to be a relief for them. (Dahl, 2018; Garåsen & Kjeøy, 2018) These observations are similar to the findings in this study.

Research question 3: What is the impact of Remote Patient Monitoring on the relationship between the spouses?

The literature review in this study found that there are a limited amount of studies addressing the impact of remote patient monitoring on the relationship between the older spouse and their partner. One of the studies found also points specifically to the lack of attention that has been given to “either the domestic relationship context in which such technologies are carried out or the impact of telemonitoring on existing relationships” (Whitfield et al., 2013).

To investigate possible impacts of the remote patient monitoring on the relationship the informants were in the interviews asked if they have experienced any changes in the dynamics of the relationship as a result of the Remote Patient Monitoring.

“... we have been married for more than 50 years”

When asked if they feel that the Remote Patient Monitoring service has in some way changed any dynamics between them as a couple, the immediate responses of three of the informants is that they haven't experienced any changes to their relationship as a result of the Remote Patient Monitoring.

One informant says:

“Everything is more or less the same, the daily routines just moves along (...), we are as fine as we can be to put it like that”

Another elaborates:

“No, it really hasn't. Everything is just the way it was – we have been married for more than 50 years – so one knows each other well –so there is no difference there”.

A third says:

“Oh, we're much too old and secure for this to play a role like that..”

These quotes may indicate that there, among the informants in this study, might be a limited room for or potential for Remote Patient Monitoring to impact on long standing relationship dynamics or routines in the relationship between the spouses.

Bregendahl and Laustsen show that the couples were positively affected by the telemonitoring regime, as it gave them a shared project and a new common interest (Bregendahl & Laustsen,

2016) and Rodgers et al. also describe that the work related to telecare service is viewed by the couples as a team effort (Rogers et al., 2011, p. 1082).

As was found in this study and outlined under the description of roles and responsibilities, Remote Patient Monitoring does in many cases become a team effort, in the initial stage to a larger degree than in the operational stage, and for some informants more than others. Still, in both stages there was some form of team approach to the Remote Patient Monitoring.

However, when talking about impacts on the relationship, the informants in this study are not as explicit about, or maybe not even conscious of the relevance, of such “team-efforts” or “shared projects”.

One informant in this study, does however, describe the processes around the measurements to provide them as a couple with a common activity, they can refer to in a humorous manner: *“Aren't you gonna measure me soon?”*.

Still, the main impression is that, although there are observed team-efforts among the informants and their spouses in the remote patient monitoring processes that could be considered parallel to findings in the literature, this form of impact on relationships is not one that is reflected upon by the informants.

Moreover, the literature indicates that Remote Patient Monitoring may impact couples by reducing the level of conflict (Bregendahl & Laustsen, 2016). In Bregendahl and Laustsen, the level of conflict is reduced because the remote patient monitoring scheme ensures that there is someone else watching and looking after the patient. The nurses secure compliance to a necessary regime for the ill spouse, and this is no longer the responsibility of the spouse, and because of this the conflict level was found to be reduced.

This is also found to occur as a result of Remote Patient Monitoring by one of the informants in this study. The informant explains that because the nurses now watch and monitor the partners condition and keeps an eye on the measurements, and also secure that relevant medical actions are taken when necessary, the informant no longer has to be the one that nags the spouse. The informant finds that this reduces conflicts in the relationship. One of the health care professionals interviewed in this study, also argues that Remote Patient Monitoring has the potential to change the dynamics between the two spouses because one feels more secure, and the conflict level is reduced due to someone else also having responsibility for the ill partner. At the same time, this informant also emphasize that people

are very different, and he or she has observed irritation and conflict between some couples as a result of having to adapt to the remote monitoring regime.

It has also been argued in the literature that the knowledge the patient and the family caregiver acquires about the health situation of the user, as a result of the Remote Patient Monitoring, can provide a common platform of communication and ensure a common knowledge of the disease (Intro International & Arkitektur-og designhøyskolen i Oslo, 2016). There are no overall findings in this study that describe the same impacts on relationships.

However, there is a comment made by one of the informants that illustrate a related effect. When asked if there had been a change in the dynamics between them as a couple, one informant replied:

“Yes, in regard to the measurements and that, now we can sort of joke around about it: “what have you done now? It’s [the pulse] up again...”, “aren’t you going to measure me?” “Don’t you have a pulse?” and stuff like that”.

This quote perhaps indicates that increased knowledge may facilitate humour in the communication between the spouses and enable conversations on a serious and emotional subject.

To summarize, this research question intended to uncover if Remote Patient Monitoring has impacted the relationship between the spouses. This study has identified some effects and possible impacts on the relationship between spouses as a result of Remote Patient Monitoring. Some of the study’s findings are in line with the conclusions of previous research. There are however no clear findings from the interviews on overall impacts on the relationships and the main impression is that, from the perspective of the spouse, the relationship has to a limited degree been impacted by Remote Patient Monitoring.

As illustrated by the quotes of the informants at the beginning of this section, it might seem that in long standing relationships, as all of the informants in this study have experienced, the existing relational structures and dynamics impact the way in which the remote patient monitoring is adapted, rather than the other way around. This might be an inherent feature for the age-group examined in this study. In Chiang et al.’s study on the effectiveness of telecare, it was found that telehealth care had no significant effect on the relationships between the family members (Chiang et al., 2012), and the findings in this study can be seen to support this.

Research question 4: How does Remote Patient Monitoring impact quality of life related aspects for the spouse?

In this thesis the quality of life related aspects examined were the following; mastery, security, worry and concern, freedom and social and physical activity. The findings for each of these aspects will be presented in the following section.

Mastery

Mastery is one of the main outcomes that is sought for both users and family caregivers in the context of welfare technology and remote patient monitoring. Mastery is in this study understood as control and knowledge in relation to the condition of the spouse, their feelings of independence and their ability to manage this situation and their perceived ability to plan in their everyday life.

Knowledge, control and self- management. When asked if Remote Patient Monitoring had provided them with a change in their knowledge and control over their situation and spouses' condition, four of the five spouses experience a positive change. Three of these four informants were in particular oriented around this factor, and their replies were the following:

« Yes, certainly, because I was very confused, because he was so ill and fell over and couldn't talk or explain and, I was like "what's happening now?", "Is it the blood pressure now?" ... but now I can just measure it ... I can measure it several times a day if I'm uncertain »

“Yes, I'd say so, because we now have an overview of the oxygen saturation in the blood and so on, it is something that we measure every day, so we have the control (...) we know that the percentage is supposed to be so and so - and as I have said before, it has happened that [spouse]has been a little low - so now we have a better control in that regard.”

« Yes, or you can say that now you have a much better control because of the equipment – and you can keep an eye on it all the time if there are any needs in regard to the blood pressure... I think that is very good »

A fourth informant also describes an increase in and importance of knowledge and control, but the informant also describes a lesser need due to a relative stability in the condition of the spouse.

Better knowledge about of the condition of spouse for the spouses is also an element emphasized by both of the informants working in the health services. They highlight that

many obtain a better overview of both the current health situation, the development of the situation over time, as well as get a pointer to how the spouse is feeling at a given point in time on the basis of specific measurements taken at a given time. Although being cautious about making judgements on the overall impact in a grave situation for some older caregivers, one of the health care personnel informants explains that the knowledge may also give the spouse something specific to focus on in a complex situation and give input to a more detailed information about variations on the condition during the course of the day.

These examples clearly portray an increase in knowledge and control over the health situation of their partners as a result of the Remote Patient Monitoring, and also that this impact both is and have the potential of being of importance to the spouses. However, when asked if they felt that Remote Patient Monitoring had affected their ability to manage the situation, the spouses are not as uniform in their responses. Only two of the informants claim that Remote Patient Monitoring has increased their ability to handle the situation.

Independence. The informants were further asked if Remote Patient Monitoring had impacted on their independence in relation to the condition of the spouse, and here the informants diverge in their perception of impacts in this regard. Three of the spouses experienced increases in their independence. One informant explains that Remote Patient Monitoring has provided independence, associating the independence with both increased knowledge and control, but also not having to rely on visits to the doctor's office in order to conduct the measurements. A second informant also emphasizes the reduction of necessary doctors' visits as element in this regard. The third informant who finds that Remote Patient Monitoring has increased independence in terms of the management of the partners condition, also partially ties this impact to an increase in the knowledge and control over the health situation. And, like the first examples, this informant also associates this independence with not having to rely on visits to the doctors' office. In addition, this third informant also underlines the response centres backing and feedback on the measurements as an aspect of increased independence. The element of support from the response centre can be argued to challenge the element of independence. However, as one of the health care personnel informants also explain, such support and contact can also contribute to the spouse being able to implement early measures themselves at home, instead of having to go to the doctor, achieving an increase in independence in that regard. The two last informants, when asked about possible experiences of a change in independence, do not find that their independence has been impacted by Remote Patient Monitoring.

Predictability and planning. Looking at possible impacts on the level of predictability and ability to plan their everyday life as a result of the Remote Patient Monitoring, the data from the interviews of the spouses show that only one informant describe an impact. The positive impact as a result of Remote Patient Monitoring experienced by this one informant is still a limited one as additional condition on the side of the ill spouse largely restricts this positive impact. The other four informants do not experience a change in predictability and ability to plan. These findings differ in comparison to previous literature, that portray a normalisation of everyday life (Bregendahl & Laustsen, 2016).

A lack of impact on predictability and planning may originate in or be a result of many different things, but two aspects that emerged from the interviews are worth noting. One of the informants, when asked if there had been a change in predictability and ability to plan, stated:

“No, absolutely not, it's some of the things that strains the most - the fact that we don't have the opportunity to plan anything, it all depends on the condition on a given day, if one can do things or not.”

As illustrated here, the potential of Remote Patient Monitoring to have a positive impact on planning and predictability is restricted by the condition of the ill spouse.

Another aspect that emerged was that the lack of positive impact on predictability and planning could also be a result of an already predictable and routine-oriented lifestyle. When asked if Remote Patient Monitoring had increased their predictability and ability to plan, another informant replied:

“No, I don't think so, because mostly we just visit our kids and grandkids and things like that, so that works just fine”

Mastery, and a possible impact on mastery due to Remote Patient Monitoring, has in this study been examined on the basis of several aspects; knowledge, control and ability to handle the situation, independence and ability to plan. The most obvious impact is that on knowledge and control, where all but one informant experiences an increase in knowledge and based on their descriptions. This impact seems of importance to the spouse's control of the situation. This is partially aligned with the findings in Keanely et al.'s study on telecare for diabetes, heart failure and COPD, where it is argued that telecare taught the family caregivers more about managing their partners condition and led to them taking a more active role in self-management (Kenealy et al., 2015). However, in this study, operationalisation of

this increased knowledge into increased or improved self-management is less prominent, as only two find that Remote Patient Monitoring has provided them with an improved ability to handle the condition of their partner. In regard to independence, this study further finds that three spouses experience that Remote Patient Monitoring has increased their independence. When looking at predictability and ability of planning, only one informant describes a partially positive impact.

Security

The five older spouses all experience feelings of increased security as a result of Remote Patient Monitoring. One informant to a lesser extent than the others, but on an overall level an increase in security is portrayed, and the same applies for the feeling of support. Also, the two informants among the health care personnel have a clear impression of increased security for the spouses. On the question if he/she, based on experience, had the impression that Remote Patient Monitoring contributes to a feeling of security the reply is:

“Yes – of that I am convinced (...) It is beyond any doubt”.

There are however differences in regard to the aspects the informants attribute the increase in security, this study has identified three factors that provides the basis for increased security.

Increased knowledge and control. One factor that four of the five informants highlight in regard to mastery was the knowledge that they had gained on the condition of their spouse as a result of Remote Patient Monitoring. Increased knowledge is for three of the informants also a factor that leads to increased feeling of safety. However, increased knowledge is not an aspect that alone leads to an increased feeling of security, among the three that mentions this as an aspect of security, knowledge seems a secondary or tertiary aspect, following two more prominent aspects.

“Someone in our corner». One of the two most prominent factors in the experience of increased security, which is highlighted by all the seven informants, is that they are provided with a feeling of having someone in their corner under Remote Patient Monitoring.

This can be illustrated by the following statements by four of the informants:

“...I was very insecure and afraid of doing something wrong before, I was listening and listening if [spouse] was breathing and if there was any change, so I thought that this is something we have to apply for. And we did, and [nurse] came quite quickly (...) They have

attended to us so well. [Nurse] has been here several times, and they call(..), so you really feel that you have someone who can reassure you”.

« It’s just that now there are more of us tending to this, it gets shared in a way(..) it’s a reassurance really – they sort of provide supervision»

«...if there are any irregularities or if the blood pressure is high – they call at once – that is really great - we have a backing there!”

“...but now that [spouse] has the remote patient monitoring, then suddenly a nurse can appear at the door, a professional and an authority – and [spouse] doesn’t just say “yeah, yeah, yeah” to the nurse. [Spouse] takes the nurse seriously. That is for me very positive”.

An important dimension of security for four of the spouses in this regard is further their relationship with the personnel at the response centres. In the interviews with the spouses the personnel from the response centres are frequently featured by their first names and in a voice that depicts a feeling of having close acquaintances with the persons here. The spouses also highlight the positive features that they find the personnel to have, in some cases praising them for these features. Visits by the personnel to their homes are also highlighted positively by the spouses and seen as some form of prerequisite for the close acquaintance or relationship. The personal meetings or encounters do not seem to be required to be frequent to enhance the informants’ security. Most of the dialogue between the personnel and the user and/or the spouse is by routine based on either chat or telephone or video, but some form of initial and/or recurring personal contact seems to be important for the spouses.

Increased medical follow- up. A further security enhancing factor identified in this study is the experience of increased medical follow-up. This factor is emphasized by all of the informants, all of which claim that the medical follow- up of their spouses have improved as a result of the Remote Patient Monitoring. This is exemplified by the following statements from the interviews with the five older spouses.

“Yes, because when that transmission goes through with blood pressure, oxygen saturation, and pulse, they respond: “good values”, “fine values”, “now it’s a little high”. Once it was very high and then [nurse] writes “what has happened now?”(....) So we know that they see, they go through this every day and lets us know if it is high or low or if it is something we need to correct(..) I felt very alone and very insecure and scared too, and we could not go to the doctor every time [spouse] was coughing a lot, but still “is there something about the

heart?” “Is there anything about blood pressure?” (...) If there is something I am unsure of I write and [nurse] answers right away.”

“Yes, I would say that - if there are irregularities and that the blood pressure and that is slightly elevated - then they call right away - so it is very good - then we have a backing there - and that's very okay”

“Yes, I would to say so, because the response centre - when it is a bit like that, they always contact us and talk to us - and so it is very good I'd say”

“ ..if they see that [spouse] is a bit low then they call and they have a chat and stuff like that, of course it's better follow-up (...) this is at least an easily accessible offer for advice and to have someone to ask if one is anxious and those kinds of thing, and one can avoid having to see the doctor – and getting the him on the phone is not possible”

“...[Spouse] had stressed badly one day and they had forgotten to do the measurements, than when [Spouse] took the measurements and they were not ok and then the nurse called and wondered "how are you doing?". It was the blood pressure that had been too high and they saw it straight away. Also, the fact that they follow up on [spouse] immediately is absolutely fantastic”

All of the spouses describe an improvement in the medical follow-up of their spouses. The improvement is related to different elements. Some say that the health care services have become more easily accessible after Remote Patient Monitoring, some point to the fact that they are provided with answers quickly and others state that it is because Remote Patient Monitoring provides advice on a regular basis. Many attribute the improvement to no longer having to wait for an appointment with the general practitioner, some also add that the general practitioner is challenging to get in contact with. Others highlight the fact that now it is the health care personnel that initiates contact with them, and not the other way around.

Finally, the spouses appreciate the fact that the health care personnel both watches, monitors and attends to their partner and their situation on a regular and predictable basis.

One of the health care personnel informants also stresses the importance of increased medical follow up for boosting the experience of security:

“All this is associated with a lot of anxiety and uncertainty, and before [Remote Patient Monitoring] a patient could be informed about his/her condition every 4th month, when seeing

a specialist, now he/she gets the information every day – of course that provides and extreme sense of security – now they know – everyday”

This study has found that the Remote Patient Monitoring has provided the older spouses with a feeling of increased security. This is in line with the findings of previous research and the conclusions of the reports published in the Norwegian Remote Patient Monitoring Project, where family caregivers were found to experiencing increased security when their family member received remote patient monitoring services (Dahl, 2018, p. 18; Garåsen & Kjeøy, 2018, p. 14; Intro International & Arkitektur-og designhøyskolen i Oslo, 2016, p. 32).

Furthermore, this study found that this increased security may be attributable to three factors. The two most important factors are the feeling of having *someone in their corner* and the *increase in medical follow up*. These factors are also pointed to in the previous literature. In the study looking at family caregivers of heart failure patients receiving home care nursing, the families that received tele- management support found it to make them feel more secure. They described the fact that the nurses are monitoring the patient, and will make contact and give instructions on what to do, was a comfort for them (Saunders, 2012, p. 86).

In Bregendahl and Laustsen’s study it was also found that the telemedical rehabilitation scheme created a feeling of security for the family caregivers in their everyday life, and that this feeling was largely connected to the nurses’ remote monitoring of the patient (Bregendahl & Laustsen, 2016, p. 138). In Jones’ study, examining different perceptions of safety among actors in a home care context, caregivers emphasized the meeting of complex care needs as an important factor in their understanding and definition of safety. Findings in this study about the increase in medical follow-up and its impact in the older spouses feeling of security, may also illustrate the caregiver’s definition of safety as described by Jones.

Chiang et al.’s study claims that the knowledge and control that the measurements provide for the family caregivers is a main factor for increased feelings of security. The element of increased knowledge and control is also found to be a factor providing a sense of security in this study, but to a lesser degree than the two other factors. Chiang et al. however also highlights increased medical follow-up and close contact with the nurses as factors impacting positively on security (Chiang et al., 2012) .

Worry and concern

Regarding the question of the remote patient monitoring's impact on the level of worry or concern for the spouses, responses from informants diverged. Three of the five spouses reported that Remote Patient Monitoring had led to a lower level of worry or concern.

When asked if Remote Patient Monitoring had affected their levels of worry, the replies of these three informants were phrased in the following way:

«Yes, absolutely(...)I can just let all that be, because it tends to itself, and I can rather use my energy on the other things”(...) It has been a great relief to get this”

«I would say yes, because we have more control in the situations, and at the response center they have contact with our doctor, so if something happens, then it is kind of shared”

«Well, you have more control over both this and that, especially when it comes to the blood pressures, so yes”

On the other hand, there are the two other informants who do not experience a change in the level of worry as a result of the Remote Patient Monitoring. The two differ in regard to reasons for lack of impact. On the one side, the older spouse does not feel that there is a need for worry in their situation and is not at all worried. This seems primarily a result of a stable condition on the side of the spouse. However, based on the data from the interview, it can also be interpreted to partially be a result of a personal trait on the side of the informant. The other informant who does not experience an impact on the level of worry and concern explains the reason for the lack of impact with the condition of the spouse. In this case the condition of the spouse is of such a character that the Remote Patient Monitoring is found by the informant to be unable to provide relief.

A reduction in the level of worry and concern was described by three of the five spouses in the study. They highlighted different explanations for the reduction, two emphasized the control they had gained over the health situation as a reason, while one highlighted the sharing of responsibility with the health care personnel at the response centre and improvement of medical follow-up as reasons for the feeling of relief.

Bergendahl and Laustsen's study shows that the family caregivers, under the telemedical rehabilitation and remote monitoring, experience a reduction in the level of worry in their everyday life, and that this is due to the nurses' support and control through the telemedical

equipment and not having to worry about their spouse complying to the rehabilitation scheme, as this is covered by the nurses' monitoring. (Bregendahl & Laustsen, 2016, p. 138 & 139). This is in line with the findings in this study, in the cases where a reduction in worry has occurred. However, the aspect of control impacting on the reduction of worry is not mentioned in the Danish study. In Karlsen et al.'s study of experiences among older adults and their caregivers receiving telecare services, family caregivers did also experience ease in the initial phase of the service, although only temporarily (Karlsen et al., 2018, p. 1). As seen in the examples, two informants in the study has not experienced an impact on the level of worry, and this lack of impact may be due to aspects affecting individual contexts, personal traits or the condition of the spouse.

Freedom and social and physical activity

In previous literature covering both Remote Patient Monitoring and other kinds of welfare technology it has been argued that spouses and family caregivers may experience an increased sense of freedom and ability to partake in social and physical activity. Bregendahl and Laustsen found that family caregivers have more time for themselves due to the flexibility of the monitoring and the telemedical rehabilitation set up, and also that family caregivers achieve more freedom when their partner, through the telemedical rehabilitation services, is more active in their own treatment (Bregendahl & Laustsen, 2016, p. 134 & 140). Thygesen and Moser also point to impacts such as increased independence and possibility of living a more active life for the family caregiver resulting from the welfare technology GPS-localisation (Thygesen & Moser, 2014, p. 15).

Notably, and in contrast to the literature, none of the spouses in this study find that their freedom, their time for themselves or their social and physical activity level has been impacted, either positively or negatively, by the Remote Patient Monitoring. However, the informants mention different reasons for this lack of impact. In the case of one of the informants the lack of impact is seen a result of a stable condition on the side of the spouse and a relatively normal and stable life situation, limiting the potential for impact. Another informant highlights the graveness of the spouse's condition and unpredictability in their daily life as a result of this, as a reason for the Remote Patient Monitoring's lack of impact on his or her freedom and personal space. A third informant portrays a routine-oriented lifestyle and daily life, in which the couple predominantly operate as a unit, limiting the potential for impact on freedom and me-time for the spouse. Another informant explains the lack of impact with a strong restriction on me-time in general due to other serious health problems

experienced by his or her spouse. However, the informant indicates that if the condition of the spouse was limited to those that are treated through Remote Patient Monitoring, then there might have been a potential for impact on freedom and activity as a result of this welfare technology.

In an interview with one of the health care professionals, the impact of Remote Patient Monitoring on freedom and activity was described in a way that is more in line with the literature. Based on experience, observations and feedback from spouses and relatives, the informant's impression was that Remote Patient Monitoring definitely impacted positively on freedom and activity:

"..They felt more free and could do more their own thing, because now there were somebody else there to receive or notice if there were any signals".

Chapter 5 - Summary and Conclusion

Aging population, increases in chronic diseases and a projected shortage of health care personnel are challenging current care models. Welfare technology and family caregiving are in this context both commonly assigned important roles in the building of a sustainable health care and care model for the future. Remote patient monitoring is one of the welfare technologies that is implemented and tested in Norway. Family caregivers are also defined as important actors and stakeholders in the welfare technological context, and there are also indications that they are important both in regard to accept of the technology, successful implementation and sustainable use of the welfare technology. Even though the importance of family caregivers is substantiated, there is a limited amount of literature on the roles of and impacts on family caregivers. This applies for both welfare technology in general, but also Remote Patient Monitoring in particular, and research on the topic is therefore called for. From the government's side outcomes for family caregivers are also sought in the implementation of welfare technology.

This thesis has focused on a sub-group of the family carers, namely older spouses. The aim and main concern of this study was twofold. It sought to shed light on both the roles of and the impacts on the older spouse when their chronically ill partner receives Remote Patient Monitoring as a municipal health care service. In order to examine the role of and impacts on the older spouse in remote patient monitoring in an informed manner, a document analysis was conducted aiming to identify relevant themes and questions for this study. A thematical and conceptual framework was developed from the findings in this document analysis. This framework is the basis of both the research questions, as well as the data collection and data analysis.

The research questions examined in this study were; What are the roles and the responsibilities of the spouse in Remote Patient Monitoring and do they have the needed competence? How does remote patient monitoring impact the care burden of the spouse? What is the impact of Remote Patient Monitoring on the relationship between the spouses? And, how does remote patient monitoring impact Quality of Life related aspects for the spouse?

The Roles of the Spouse

This study has shown that there are a variety of roles the spouses may have, and that these roles may change between different stages. At the very start of the service and also when introduced to the service, the older spouse and the user/recipient seem to do this as a unit in a form of joint venture. The spouses are both characterized by being very positive to the Remote Patient Monitoring at this point, and this positiveness is to a large degree based on the view that this service is a rational and sensible service for them, their partner and their situation. On the basis of their role at the point of entry, their positivity and maybe most importantly their rationality, the spouses can be argued to play an important role for the acceptance of the service by the user/recipient and a sustainable entry into the service.

Compared to the initial stage, variation in the roles of the spouses, is a main feature at the operational stage of Remote Patient Monitoring. There are those that describe their role as both large and critical and others who perceive their involvement as marginal to none, or state that their involvement is merely on an ad-hoc basis. What is notable in this regard, is that in some cases the role of the spouse may be of such a scope and size they can be argued to have the role of main operator for the service in the domestic sphere.

Further, this study identified a range of possible tasks and responsibilities that might be acquired by the spouse as a part of the Remote Patient Monitoring service. The tasks, both small and large, ranged from Medical instruments operation, Registration and transmitting of data, IT and Operational Support, assisting administratively, communication responsibilities, hospitality and human relations and just being a companion. The list of tasks and responsibilities identified here is not exhaustive but may still illustrate some of the variety of responsibilities for this group. What is also worth mentioning is that all spouses, regardless of the size of their role, in fact have acquired task or responsibilities, and that some of these tasks are also potentially important to the sustainability of the service. This finding is relevant to consider as it seems that the role of the spouse develops informally in the domestic sphere, rather than in a formal one, and is adjusted to individual domestic dynamics.

When examining the competences that are required of the spouse under Remote Patient Monitoring technology, the main impression from this study is that this technology is found to be uncomplicated and easy to use. Most also had experiences with both or either computers and tablets from before, but there were however still some hesitation and reluctance expressed towards the use of the tablets. In this study however, this hesitation seems to be a reason for

the spouse distancing from the process, rather than partaking in them with a feeling of inadequacy. Among the spouses, there were no reluctances or qualms noted in regard to the use of the medical equipment that are part of the set up.

The Impacts on the Spouse

The impacts of Remote Distance Monitoring examined above are the impacts on the care burden of the spouse, on the relationship between the spouse and their partner, and on quality of life related aspects. All these topics are informed by previous literature and studies, government documents and project reports, and are derived from the thematical framework of this study (See Chapter 3). For instance, the quality of life related aspects includes features that are derived from government documents and project reports concerning implementation of welfare technology in the Norwegian care context, explicitly stating desired outcomes on the side of the family caregiver.

An overall conclusion from this study is that Remote Patient Monitoring reduces the care burden for many spouses. However, the spouses do not experience a change in the scope of or time used for of their caregiving, neither a reduction nor an increase in the burden. The fact that none of the spouses experience an increase in the time and scope of their caregiving activities can be viewed to be notable, as findings here have also shown that all the older spouses have actually acquired new tasks as a result of the remote patient monitoring service. This finding is also contrary to what literature has found to be the case for other kinds of welfare technology. Notably, I have presented some possible explanations in this study. It might be that this is a feature that is specific for the sample in this study only and is not representative beyond this group. Also, it might also be that this finding is specific for the age group in questions, as *time* might not be as scarce a resource for them as for younger age groups, and not a point of focus.

This study found that there were three factors leading to reduction of the care burden for the spouses. The most prominent factor is the experience of *sharing responsibility* with someone. The spouses found great relief in that they under the remote patient monitoring no longer had the feeling of being alone with the responsibility for their ill partner, as the responsibility is now shared with the personnel at the response centres. A second important factor for the reduction in care burden was the *improved access to health care personnel*. The third factor,

however somewhat less prominent, was explained to be the *control and knowledge* of the condition of the ill spouse, obtained as a result of the remote Patient monitoring.

When examining impacts on Quality of Life Related Aspects for the spouse, the most prominent impact on the informants was the increases in feelings of security and support. All of the informants in this study underline that increased security and support is an impact of the Remote Patient Monitoring. This study further concludes that this increased security was attributable to three factors. The two most prominent factors are the feeling of having *someone in their corner* with whom they can share responsibility and the experience of *increased medical follow up*. With regard to the sharing of responsibility with someone, a close and personal connection with the personnel at the response centres seemed a core component. The feeling of increased medical follow-up is associated with increased access to and frequency of contact with health care professionals, as well as the continuous monitoring by professionals and that contact is initiated by the health care personnel. *Increased knowledge* is also a factor that leads to increased feeling of security for the informants, however as a secondary or tertiary aspect, in combination with the two other aspects.

Impacts on mastery was assessed on the basis of impacts on control and knowledge, on the perceived ability to handle their situation, independence and ability to plan in their everyday life. The most obvious impact was on knowledge and control, as many of the spouses found that Remote Patient Monitoring provides them with increased control and knowledge about their partners condition and situation. However, operationalisation of this increased knowledge into improved ability to handle the condition of their partner, or self – management, is less prominent among the spouses in this study. This is also the case for the feeling of independence. Also, when looking at impacts on ability to plan, only one informant describes a partially positive impact. For the three other quality of life related aspects; worry, freedom and social and physical activity, the impacts of remote patient monitoring vary. A reduction in the level of worry and concern was experienced by some: knowledge and control, sharing of responsibility and increased medical follow-up were also highlighted as reasons for the feeling of relief. None of the spouses in this study find that their freedom, their time for themselves or their social and physical activity level has been impacted, either positively or negatively, by Remote Patient Monitoring.

In regard to impact on the relationship between the spouses there were no clear findings on overall consequences, and the main impression was that the relationship, from the perspective of the spouse, to a limited degree had been impacted by Remote Patient Monitoring. It might

seem that for the informants their long-standing relationships, the existing relational structures and established dynamics impact the way in which the remote patient monitoring is adapted to their environment, rather than that Remote Patient Monitoring impacting on these structures or dynamics.

Conclusion

This study has found that the older spouses play an important role in the initial stage of the service, and that they are contributors in the operational stage of the service as well. In some cases, the spouse can even be argued to be a main operator in the domestic sphere. In other cases, the involvement of the spouse is more marginal. This study has also identified a range of different tasks and responsibilities that may be acquired by the spouse under Remote Patient Monitoring. The tasks are both small and large, but regardless of size, some of the tasks distributed to the spouse can be argued to be of relevance to the sustainability of the Remote Patient Monitoring Service. Another important element to consider is that all the spouses in this study, also those who find that their role is marginal to none, acquire tasks or responsibilities. Those who are involved in the use of the remote patient monitoring technology find it uncomplicated and easy to use, but still there are some hesitations towards the “computer-stuff”. In cases where the informants are somewhat reluctant to use computer technology, it seems to be a reason for stepping back from the processes rather than participation with a feeling of inadequacy.

When examining the impacts of remote patient monitoring on the older spouse, the most prominent impacts is the experienced reduction in care burden and among the quality of life related aspects, the increased feelings of security. Positive impacts on mastery are also shown in terms of increased control and knowledge. However, in regard to improvements in the ability to handle their situation and increases in their independence, the findings in this study are not as unambiguous. Varying and limited levels of impacts were also found in relation to the other quality of life related aspects; ability to plan, worry, freedom and social and physical activity. This might be a product of many factors, but the condition of the partner, either grave or stable, obviously defines the potential for impact to occur. Another factor shaping the potential impact and also limiting it may be a lifestyle of predictability and established routines, a lifestyle that may be a characteristic associated with the age group in question. Related features, such as long-standing relational dynamics and routines, also seem to shape the potential impact on the relationship between the spouses. Like the abovementioned

aspects, this study found that relationships were described by the spouses to be impacted to a limited extent by the Remote Patient Monitoring.

Moving back to the positive impacts on care burden and feeling of security, this study found that there are in particular two common and important factors leading to an improvement of both these two aspects. The most important factor is the sharing of responsibility. The fact that the spouses under Remote Patient Monitoring feel that they now share the responsibility for their ill partner with the health care personnel at the response centre, takes both a large load of their shoulders as well as it provides them with a feeling of security. For the spouses the health care personnel at the response centre seems to constitute the core of the service, on whom they both rely and turn to when uncertain. This close connection to and reliance on the response centre might also provide insight as to why, in this study, there is a limited impact of remote patient monitoring on perceived self-management and independence on the side of the spouse. Secondly, the experience of increased and improved medical follow-up under Remote Patient Monitoring is another common and important factor for both care burden and security.

To summarize, this study concludes that the spouses have important roles under Remote Patient Monitoring. The older spouses play an important role in the initial stage of the service and regardless of the magnitude of their role, they are distributed tasks and responsibilities of various kinds in the operational stage. Some of these tasks may be critical to the sustainability of the service. The spouses are also impacted by Remote Patient Monitoring, but on some dimensions more than others. The main impacts experienced by the spouse as a result of Remote Patient Monitoring were increased security and care burden relief. Both impacts notably found to arise as a result of the professional, human constituents of the service, and not as much by the technology itself.

[Avenues for further research](#)

In addition to the empirical contributions of this study, it may also provide a thematical framework that can be used and elaborated on in other studies of the impact of welfare technology on family caregivers. In this study, the time frame and challenges related to recruitment meant that it was only possible to interview a limited number of informants. However, this study and the thematical framework developed here could generate hypotheses and be a point of departure for quantitative survey-based research or large-scale qualitative studies, that may provide a more representative and richer picture of the impact of remote patient monitoring (or other forms of welfare technology) on family caregivers.

References

- Akrich, M. (1992). The De-scription of Technical Objects. In W. E. Bijker & J. Law (Eds.), *Shaping technology/building society: Studies in sociotechnical change* (pp. 205-224): Inside Technology series. Cambridge and London: MIT Press.
- Andersen, K. L., Strøm, A., Korneliussen, K., & Fagermoen, M. S. (2016). Family caregivers to a patient with chronic heart failure living at home: «co-workers» in a blurred health care system. *Sykepleien.no/, Forskning 10.4220*(Sykepleienf.2016.57818).
- Andreassen, H. K., Dyb, K., May, C. R., Pope, C. J., & Warth, L. L. (2018). Digitized patient-provider interaction: How does it matter? A qualitative meta-synthesis. *Social Science & Medicine, 215*, 36-44. doi:10.1016/j.socscimed.2018.08.036
- Ausen, D. (2013). *Trygge spor : GPS-løsning og tilhørende støttesystemer for personer med demens innovasjonsprosjekt i offentlig sektor* SINTEF rapport (SINTEF : 2006- : online), Vol. SINTEF A23878.
- Baanders, A. N., & Heijmans, M. J. W. M. (2007). The impact of chronic diseases: the partner's perspective. *Family & Community Health, 30*(4), 305-317.
- Bookwala, J., & Schulz, R. (1998). The role of neuroticism and mastery in spouse caregivers' assessment of and response to a contextual stressor. *The Journals of Gerontology, 53a*(3), P155-164. doi:10.1093/geronb/53B.3.P155
- Bowen, G. (2009). Document Analysis as a Qualitative Research Method. *Qualitative Research Journal, 9*(2), 27-40. doi:DOI 10.3316/QRJ0902027
- Bregendahl, A. W., & Laustsen, S. (2016). Pårørendes oplevelse af hjertepatientens telemedicinske rehabiliteringsforløb. *Klinisk Sygepleje, 30*(2), 129-142. doi:10.18261/issn.1903-2285-2016-02-06
- Bryman, A. (2012). *Social Research Methods* (4th ed.). New York: Oxford University Press.
- Bull-Berg, H., Halvorsen, T. U., & Hem, K.-G. (2015). Evaluering av velferdsteknologi - Et helhetlig rammeverk for effektevaluering.
- Byrne. (2004). Qualitative Interviewing. C. Seale (ed.). *Researching Society and Culture. Second Edition. Thousand Oaks: SAGE*, 179-193.
- Chiang, L.-C., Chen, W.-C., Dai, Y.-T., & Ho, Y.-L. (2012). The effectiveness of telehealth care on caregiver burden, mastery of stress, and family function among family caregivers of heart failure patients: A quasi-experimental study. *International Journal of Nursing Studies, 49*(10), 1230-1242. doi:10.1016/j.ijnurstu.2012.04.013
- Dahl, M. (2018). *Sluttrapport Mestry, Nasjonalt prosjekt for utprøving av velferdsteknologiske løsninger for personer med kroniske sykdommer* Retrieved from <https://helsedirektoratet.no/Documents/Velferdsteknologi/Sluttrapporten%202018%20Mestry.pdf>
- Directorate of Health. (2019). Velferdsteknologi. Retrieved from <https://helsedirektoratet.no/velferdsteknologi>
- Garåsen, H., & Kjeøy, M. A. (2018). *HelsaMi+ - PROSJEKT FOR AVSTANDSOPPFØLGING AV KRONISK SYKE 2015-2018 - SLUTTRAPPORT* Retrieved from <https://helsedirektoratet.no/Documents/Velferdsteknologi/Sluttrapport%20-%20Prosjekt%20for%20avstandsoppf%C3%B8lging%20av%20kronisk%20syke%20-%20HelsaMi+%20.pdf>
- Goldberg, A., & Rickler, K. S. (2011). The Role of Family Caregivers for People with Chronic Illness. *Medicine & Health Rhode Island, 94*(2), 41-42.
- Gorst, S., Armitage, C., Brownsell, S., & Hawley, M. (2014). Home Telehealth Uptake and Continued Use Among Heart Failure and Chronic Obstructive Pulmonary Disease Patients: a Systematic Review. *Annals of Behavioral Medicine, 48*(3), 323-336. doi:10.1007/s12160-014-9607-x

- Grut, L., Reitan, J., Hem, K.-G., Ausen, D., Bøthun, S., Hagen, K., . . . Vabø, M. (2013). Veikart for innovasjon av velferdsteknologi.
- Hesleskaug, A. M. Ø., & Tuft, T. E. (2016). Muliggjør GPS et friere og tryggere liv med demens i familien? : pårørende til personer med demens som benytter GPS-teknologi - Erfaringer og utfordringer: Universitetet i Agder ; University of Agder.
- Intro International. (2017). *Avstandsoppfølging - Delrapport 1*. Directorate of Health, Retrieved from <https://helsedirektoratet.no/Documents/Velferdsteknologi/Avstandsoppf%C3%B8lging%20-Delrapport%201%20-%20Intro%20International%20AS.pdf>.
- Intro International. (2018a). *Avstandsoppfølging - Delrapport 2*. Directorate of Health, Retrieved from <https://helsedirektoratet.no/Documents/Velferdsteknologi/Avstandsoppf%C3%B8lging%20Delrapport%202%20-%20Intro%20International%20AS.pdf>.
- Intro International. (2018b). *EFFEKTER AV AVSTANDSOPPFØLGING - Følgforskning av medisinsk avstandsoppfølging i delprosjektene VIS, Mestry, GodhelseHjemme og HelsaMi+* Retrieved from Directorate of Health: <https://helsedirektoratet.no/Documents/Velferdsteknologi/2018%20Sluttrapport%20-%201.0%20-%20Effekter%20av%20avstandsoppf%C3%B8lging.pdf>
- Intro International, & Arkitektur-og designhøyskolen i Oslo. (2016). *Velferdsteknologi i sentrum. Innføring av velferdsteknologi i sentrumsbydelene i Oslo. En kartlegging av effekten. Delleveranse 2 av 2* Retrieved from https://helsedirektoratet.no/Documents/Velferdsteknologi/Velferdsteknologi%20i%20Osentrum_delleveranse%202%20av%202.pdf.
- Jerolmack, C., & Khan, S. (2014). Talk Is Cheap: Ethnography and the Attitudinal Fallacy. *Sociological Methods & Research* 2014, Vol. 43(2) 178-209 doi:10.1177/0049124114523396
- Johnsen, E. (2017). *Sosial, digital kontakt*. Retrieved from
- Jones, S. (2016). Alternative perspectives of safety in home delivered health care: a sequential exploratory mixed method study. *Journal of Advanced Nursing*, 72(10), 2536-2546. doi:10.1111/jan.13006
- Jönsson, A.-M., & Willman, A. (2008). Implementation of Telenursing Within Home Healthcare. *Telemedicine And E-Health*, 14(10). doi:10.1089/tmj.2008.0022
- Karlsen, C., Moe, C. E., Haraldstad, K., & Thygesen, E. (2018). Caring by Telecare? A Hermeneutic Study of Experiences among Older Adults and Their Family Caregivers.
- Kelly, M. (2010). Who cares.....for the carers? *Journal of Renal Care*, 36(1), 16-20. doi:10.1111/j.1755-6686.2010.00139.x
- Kenealy, T., Parsons, M., Rouse, A., Doughty, R., Sheridan, N., Harré Hindmarsh, J., . . . Rea, H. (2015). Telecare for Diabetes, CHF or COPD: Effect on Quality of Life, Hospital Use and Costs. A Randomised Controlled Trial and Qualitative Evaluation. *Plos One*, 10(3), e0116188. doi:10.1371/journal.pone.0116188
- Lendrum, S., & Syme, G. (2004). *Gift of tears : a practical approach to loss and bereavement in counselling and psychotherapy*
- Lubkin, I. M., & Larsen, P. D. (2013). *Chronic illness : impact and intervention*. Burlington, Mass: Jones and Bartlett.
- McDonald, J., McKinlay, E., Keeling, S., & Levack, W. (2016). Becoming an expert carer: the process of family carers learning to manage technical health procedures at home. *Journal of Advanced Nursing*, 72(9), 2173-2184. doi:10.1111/jan.12984
- Milligan, C., Roberts, C., & Mort, M. (2011). Telecare and older people: Who cares where? *Social Science & Medicine*, 72(3), 347-354. doi:10.1016/j.socscimed.2010.08.014

- Ministry of Health and Care Services. (2012–2013). *Morgendagens omsorg*. (Meld. St. 29). Retrieved from <https://www.regjeringen.no/no/dokumenter/meld-st-29-20122013/id723252/>.
- Mody, L., Miller, D. K., McGloin, J. M., Freeman, M., Marcantonio, E. R., Magaziner, J., & Studenski, S. (2008). Recruitment and Retention of Older Adults in Aging Research. *Journal of the American Geriatrics Society*, 56(12), 2340-2348. doi:10.1111/j.1532-5415.2008.02015.x
- Moser, I. (2019). *Velferdsteknologi : en ressursbok* (1. utgave. ed.). Oslo: Cappelen Damm akademisk.
- Nes, R., Hansen, T., & Barstad, A. (2018). *Livskvalitet, Anbefalinger for et bedre målesystem*. (IS-2727). Directorate of Health Retrieved from <https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/1463/Livskvalitet.%20Anbefalinger%20for%20et%20bedre%20m%C3%A5lesystem%20IS-2727.pdf>.
- NOU 2011: 11. (2011). *Innovasjon i omsorg*. Retrieved from <https://www.regjeringen.no/no/dokumenter/nou-2011-11/id646812/>.
- Novak, M. a. G., Carol. (1989). Application of a Multidimensional Caregiver Burden Inventory. *The gerontologist*, 29(6), 798. doi:<https://doi.org/10.1093/geront/29.6.798>
- Nugent, P. M. S. (2019a). "Mastery Training" - PsychologyDictionary.org. Retrieved from <https://psychologydictionary.org/mastery-training/>
- Nugent, P. M. S. (2019b, April 7, 2013). "Worry" - PsychologyDictionary.org. Retrieved from <https://psychologydictionary.org/worry>
- Oxford Dictionaries. (2019). Definition. Retrieved from <https://en.oxforddictionaries.com/definition/>
- Pårørendealliansen. (2017). Pårørendeundersøkelsen 2017 Hovedfunn. Retrieved from <https://parorendealliansen.no/fakta-statistikk/>
- REC - Regional Committees for Medical and Health Research Ethics. (2019). Retrieved from <https://helseforskning.etikkom.no>
- Researchware.com. (2019). Transcription with Hyper Transcribe. Retrieved from <http://www.researchware.com/products/hypertranscribe.html#Power>
- Risjord, M. (2014). *Philosophy of Social Science -A Contemporary Introduction*. New York: Routledge.
- Rogers, A., Kirk, S., Gately, C., May, C. R., & Finch, T. (2011). Established users and the making of telecare work in long term condition management: Implications for health policy. *Social Science & Medicine*, 72(7), 1077-1084. doi:10.1016/j.socscimed.2011.01.031
- Rogne, A. F., & Syse, A. (2017). *Fremtidens eldre i by og bygd - Befolkningsframskrivinger, sosiodemografi ske mønstre og helse*. Retrieved from Statistisk sentralbyrå <https://www.ssb.no/befolkning/artikler-og-publikasjoner/attachment/328026?ts=167c714ea80>
- Roksvaag, K., & Texmon, I. (2012). *Arbeidsmarkedet for helse- og sosialpersonell fram mot år 2035 Dokumentasjon av beregninger med HELSEMOD 2012* Retrieved from Statistisk sentralbyrå: https://www.ssb.no/a/publikasjoner/pdf/rapp_201214/rapp_201214.pdf
- Saunders, M. M. (2012). Perspectives from family caregivers receiving home nursing support: findings from a qualitative study of home care patients with heart failure. *Home Healthcare Nurse*, 30(2), 82-90. doi:10.1097/NHH.0b013e3182429337
- Silverman, D. (2011). *Interpreting Qualitative Data. Methods for Analysing Talk, Text and Interaction. 4th edition*. . London, Thousand Oaks, New Delhi, : SAGE Publications.
- Skadeforebyggende forum. (2019). Definisjoner. Retrieved from <https://www.skafor.org/annet-infomateriell/definisjoner/>

- Sullivan, M. (2002). Caregiver strain index (CSI). *Journal of Gerontological Nursing*, 28(8), 4-5. doi:10.3928/0098-9134-20020801-03
- TELMA. (2019). Retrieved from <http://www.telma.no/om-prosjektet/>
- The Ministry of Health and Care Services. (2018). *Leve hele livet : en kvalitetsreform for eldre*. Retrieved from <https://www.regjeringen.no/contentassets/196f99e63aa14f849c4e4b9b9906a3f8/no/pdfs/stm201720180015000dddpdfs.pdf>.
- The Office of the Prime Minister. (2019). *The Granavolden- platform. Political platform for the Norwegian Government, formed by the Conservative Party, the Progress Party, the Liberal Party and the Christian Democratic Party*. Retrieved from <https://www.regjeringen.no/contentassets/7b0b7f0fcf0f4d93bb6705838248749b/granavolden-platform-english.pdf>.
- Thygesen, H. (2015). Hva er velferdsteknologi, og hvorfor er den viktig? – en introduksjon til velferdsteknologi- begrepet og den samfunnsmessige konteksten. *Nordisk tidsskrift for palliativ medisin, Nr. 4 – 2015 Omsorg*.
- Thygesen, H., & Moser, I. (2014). GPS-sporing i demensomsorgen. *Geriatrisk Sykepleie*, 2:2014.
- Vallor, S. (2011). Carebots and Caregivers: Sustaining the Ethical Ideal of Care in the Twenty-First Century. *Philosophy & Technology*, 24(3), 251-268. doi:10.1007/s13347-011-0015-x
- VIS- Velferdsteknologi i Sentrum. (2018). *Sluttrappport - Avstandsoppfølging av Kronisk Syke*. Retrieved from Provided by Oslo Kommune:
- Whitfield, C., Seymour, J., Plowman, J., & O'Leary, N. (2013). The place of 'family' in the delivery of telehealth. *International Journal of Integrated Care (IJIC)*, 13, 1-2.
- World Health Organisation. (2018). WHOQOL: Measuring Quality of Life. Retrieved from <http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>

Appendix 1 – Recruitment Poster

Har du lyst til å være med i et
forskningsprosjekt?

OSLOMET

**Er du over 65 år og gift/partner med en som følges
opp gjennom medisinsk avstandsoppfølging?**

Da søkes din deltakelse i et forskningsprosjekt som skal undersøke:

**«Medisinsk avstandsoppfølging: Rollen til og påvirkningen på
eldre pårørende»**

Deltakelsen vil bestå av et intervju som vil ta om lag en time på et egnet
sted.

Forskningsprosjektet utføres som en del av en Masteroppgave ved Oslo
Met (tidl. Høyskolen i Oslo) og prosjektet veiledes ved NOVA, Seksjon for
aldersforskning.

Ta gjerne kontakt på telefon: **48 19 37 83** eller på e-post:
s976323@oslomet.no ved interesse for å delta og for mer informasjon.

Telefon: 48 19 37 83	E-post: s976323@oslomet.no	Telefon: 48 19 37 83	E-post: s976323@oslomet.no	Telefon: 48 19 37 83	E-post: s976323@oslomet.no	Telefon: 48 19 37 83	E-post: s976323@oslomet.no
----------------------	--	----------------------	--	----------------------	--	----------------------	--

Appendix 2 – Interview Guides

A) Interview guide – Sample I – Older Spouses

Intervjuguide	
Masteroppgave – Solveig Bryne Castberg Stølan – 2018/2019 – Oslo Met «Avstandsoppfølging: Rollen til og påvirkningen på eldre pårørende»	
<ul style="list-style-type: none"> • Presentasjon av meg selv og masteroppgaven: SBCS, masterstudie ved OsloMet (HIOA), og skriver en masteroppgave om «Avstandsoppfølging: Rollen til og påvirkningen på eldre pårørende». • Bakgrunn: AO er en VFT som er i vinden, mye forskning på effekt på bruker og på det helseøkonomiske aspektet, men lite fokus på pårørendes rolle. Kunnskap som er etterlyst og som jeg ønsker å belyse noe gjennom min studie. • Studien baserer seg på intervjuer med inntil 10 ektefeller av personer som blir fulgt opp gjennom A.O. • Tema: Ansvar, Trygghet, mestring, livskvalitet og påvirkning på relasjon • 30 spørsmål i intervjuet og selve intervjuet vil ta ca. 30- 40 minutter. • Intervjuet dokumenteres mens vi snakker sammen; lydopptak (stenograf) + transkribering (mandag) + sletting (mandag). Sikring av anonymitet. Alt behandles med full konfidensialitet hele veien. • Informasjonsbrev, et til det og et til din ektefelle. Har du noen spørsmål? • Samtykkeskjema: Mitt rettslige grunnlag for å benytte din informasjon i studien. Når som helst trekkes, Underskrift på samtykkeskjema – det vi ordne med enten nå med en gang eller før jeg går etterpå. • Informere om full mulighet til å trekke seg under intervjuet. + om det er noe du ikke er komfortabel med å svare på er det også helt ok – da sier du bare det. 	

FAKTASPØRSMÅL	1. Hvor lang erfaring har dere med A.O.?	(hvor mange år)
	2. Hvilke forventninger hadde du til A.O. før den ble tatt i bruk?	
	- <i>Positivt eller negativt innstilt</i> - <i>Pådriver for å ta i bruk</i>	
	3. (Ikke sikkert det er enkelt å være helt spesifikk, men) Hvor lenge har sykdomsbildet som er grunnlaget for A.O. preget deres hverdag?	(hvor mange år)
4. Hvordan oppfattet du oppfølgingen fra helsevesenet av din ektefelle før avstandsoppfølgingen?		
	- <i>Fraværende</i> - <i>God eller dårlig</i> - <i>Proaktiv</i> -	

Hovedspørsmål

Rolle, ansvar og kompetanse - Ansvar	<p>1. Er du deltakende i de prosessene din ektefelle gjennomfører som en del av avstandsoppfølgingen?</p> <p>2. Hvilke deler av prosessen er det du bidrar inn i?</p> <p style="padding-left: 40px;">Er du med på alle målingene? Hvor ofte måler du?</p> <p>3. Opplever du at din tilstedeværelse er viktig for prosessene som må gjøres i avstandsoppfølgingen, som passiv eller aktiv deltaker?</p>	
Kompetanse	<p>4. Har du lært deg hvordan teknologien og måleinstrumentene skal benyttes? – eller hadde du erfaring med nettbrett og måleinstrumentene fra før?</p> <p>5. Har du fått opplæring på selvstendig grunnlag i bruken av teknologien?</p> <p>6. Kunne du sagt noe om hva opplæringen gikk ut på, hvor lang? Av hvem?</p> <p>7. Når du benytter instrumentene og nettbrettet, er du trygg på håndteringen av dette?</p> <p>8. Har det skjedd at du har måttet problemløse noe i forhold til bruken av teknologien/instrumentene, noe som ikke har fungert eller gått galt?</p> <p>9. Har dere en kontaktperson du kan ringe til dersom noe ikke fungerer?</p>	<p><i>venn med knapper og kommandoer eller litt mer famlende trykking på vilkårlige knapper</i></p>
Rolle, ansvar og kompetanse - Rolle	<p>10. Er du med på avtalene/møtene/samtalene din ektefelle har med responscenteret/ (evt. møtene med fastlegen)?</p> <p>11. Er du gitt noen spesifikke oppgaver som er formalisert i planene rundt avstandsoppfølgingen?</p> <p>12. Opplever du at du mottar støtte fra responscenteret på selvstendig grunnlag?</p> <p>13. Hender det at du tar kontakt med responscenteret selv på vegne av deg og din ektefelle?</p> <p>14. Vi har allerede vært litt inne på dette med din rolle ifht målingene og løpende prosesser.</p> <p style="padding-left: 40px;">Sett på tjenesten som en helhet - hvor viktig opplever du at din rolle er i avstandsoppfølgingen er?</p>	<p><i>Filmoppsett: hovedrolle, bi-rolle, perifer rolle, statist – rolle.</i></p>

Omsorgsomfang	<p><i>Man gir hverandre mange former for omsorg i et ekteskap, og det ytes av begge avh av behov og omstendighet</i></p> <p><i>.... men hvis vi ser på den delen av din omsorg for din ektefelle som er knyttet til sykdomsbilde og bakgrunnen for A.O:</i></p> <p>15. Har avstandspfølgingen ført til at ditt omsorgsomfang for din ektefelle er endret etter at A.O. startet?</p> <p>16. Opplever du at A.O. avlaster deg i noen av dine omsorgsoppgaver?</p> <p>17. Har du fått andre eller nye oppgaver som følge av A.O.? Måler, problemløser, motivator, andre ikke A.O relaterte oppgaver?</p>	<ul style="list-style-type: none"> - Endret karakter på oppgavene dine - Er oppgavene dine like som før A.O. - Nye oppgaver? - Tilbake til slik det var før, - endres til mer selvstendighet hos partner?
----------------------	---	--

Mestring og kontroll	<p>18. Opplever du som ektefelle at A.O er en støtte i hverdagen?</p> <p>Hva knytter du denne støtten til?</p> <p>19. Opplever du at A.O. har lært deg mer om din ektefelles helse og gitt deg bedre oversikt enn du hadde før?</p> <p>20. Opplever du at A.O. har gitt deg som ektefelle bedre evne til å håndtere sykdomssituasjonen og gjort deg mer selvstendige og uavhengige?</p> <p>21. Fører A.O. til at dere i større grad får en forutsigbar hverdag og at det er lettere å planlegge?</p> <p>22. Føler du at dere er bedre fulgt opp nå enn før A.O startet? (til trygghet!)</p>	<p>Tilfører denne tjenesten noe for deg som gjør at du føler en form for lettelse?</p> <ul style="list-style-type: none"> • Færre sykehus opphold • Færre dårlige perioder • Bedre almenntilstand • Lettere å gjennomføre avtaler uten å avlyse på kort varsel <p>Av kommunen, helsetjenestene, fastlegen? Hyppighet, mengde..</p>
-----------------------------	---	--

B) Interview guide – Sample II – Health Care Personnel

Intervjuguide	
Masteroppgave – Solveig Bryne Castberg Stølan – 2018/2019 – Oslo Met «Avstandsoppfølging: Rollen til og påvirkningen på eldre pårørende»	
<ul style="list-style-type: none"> • Presentasjon av meg selv og masteroppgaven: SBCS, masterstudie ved OsloMet (HIOA), og skriver en masteroppgave om «Avstandsoppfølging: Rollen til og påvirkningen på eldre pårørende». Bakgrunn: AO er en VFT som er i vinden, mye forskning på effekt på bruker og på det helseøkonomiske aspektet, men lite fokus på pårørendes rolle. Etterlyst og ønsker å belyse det. • Studien baserer seg på intervjuer med inntil 10 ektefeller av personer som blir fulgt opp gjennom A.O. , + et antall personer i kommuner som er med i produksjon av denne tjenesten og som besitter perspektiver på de pårørendes rolle. • Tema: Ansvar, Trygghet, mestring, livskvalitet og påvirkning på relasjon • 20 spørsmål i intervjuet og det vil ta ca. godt under en times tid. • Intervjuet skal dokumenteres; lydopptak + transkribering + sletting. Sikring av anonymitet. • Informasjonsbrev. Gå gjennom skjema til deltakeren. Spørsmål? • Underskrift på samtykkeskjema • Informere om full mulighet til å trekke seg under intervjuet. + om det er noe du ikke er komfortabel med å svare på er det også helt ok – da sier du bare det. 	

Hovedspørsmål		
	1. Hvor lenge har du jobbet med avstandsoppfølging 2. Hvilken rolle innenfor avstandsoppfølging har du hatt 3. Anslagsvis, hvor mange av de brukerne du har fulgt opp har bodd sammen med sin ektefelle?	
Rolle, ansvar og kompetanse - Ansvar	4. Oppfatter du at ektefelle i stor eller liten grad deltar i de prosessene brukeren må gjennomføre som en del av avstandsoppfølgingen? Hvilke oppgaver i prosessen er det de bidrar med? 5. Opplever du at ektefelles tilstedeværelse er viktig for gjennomføring målinger, som passiv eller aktiv deltaker? 6. Oppfatter du at det er vanlig at ektefeller er med på avtalene/møtene/samtalene ektefelle har med responscenteret/ (evt. møtene med fastlegen)?	
Rolle, ansvar og kompetanse - Rolle	7. Hvilken rolle opplever du at pårørende har i avstandsoppfølgingen? Filmoppsett: <i>hovedrolle, bi-rolle, perifer rolle, statist - rolle.</i> 8. Er det vanlig at ektefelle blir tildelt spesifikke oppgaver som er formalisert i planene med responscenteret/fastlegen/kommunen?	<i>(hovedrolle, bi-rolle, perifer rolle, statist - rolle)</i>

Rolle, ansvar og kompetanse (kompetanse)	9. Oppfatter du at det er vanlig at ektefeller får opplæring på selvstendig grunnlag i bruken av teknologien? 10. Er inntrykket ditt at pårørende er trygg på håndteringen av instrumentene og nettbrettet? 11. Har du inntrykk av at pårørende er sentrale i problemløsning dersom noe ikke skulle fungere med utstyret?	Hvordan foregikk denne opplæringen, hvor lang? Av hvem?
Omsorgsomfang	12. Har du inntrykk av at avstandsoppfølgingen ført til at omsorgsbyrden eller omsorgsomfanget ektefellene yter er endret sammenlignet med før A.O.? - større eller mindre? - Har det tilført nye oppgaver? - Redusert andre oppgaver? - Endret karakter på oppgavene?	

Mestring og Trygghet,	<p>13. Har du inntrykk av at de pårørende har opplevd å mestre hverdagen sin bedre pga. A.O.</p> <p>14. Har du inntrykk av at A.O. har gitt pårørende bedre oversikt ektefellens helse enn de hadde før A.O.? Har dette vært verdifull kunnskap for den pårørende?</p> <p>15. Opplever du at A.O. gir pårørende bedre evne til å håndtere sykdomssituasjonen og har gjort dem mer selvstendige og uavhengige?</p> <p>16. Har du inntrykk av at avstandsoppfølgingen tilfører en følelse av trygghet for pårørende som ikke var der før A.O.?</p> <p>17. Hva oppfatter du at de pårørende knytter denne tryggheten til? (personer, målinger, oversikt over tilstanden)</p>	
-----------------------	--	--

Bekymring, Stress, Frihet og aktivitet	<p>18. Har du inntrykk av at avstandsoppfølgingen ført til at ektefellene mindre bekymret for sin ektefelles helsestilstand?</p> <p>19. Har du inntrykk av at A.O. reduserer stress relatert til sykdom for den pårørende</p> <p>20. Opplever du at avstandsoppfølging har ført til mer frihet og rom for egentid for ektefellene?</p> <p>21. Har du inntrykk av at avstandsoppfølgingen ført til en endring i det fysiske og sosiale aktivitetsnivå til de pårørende?</p>	<p>Uro, bekymring, søvn</p> <ul style="list-style-type: none"> • reise vekk, gå på kino, ta opp igjen hobbyer, ta opp igjen kontakt med venner, mer tid for deg selv, mer rom for å planlegge? • mer sosialt liv, mer fysisk aktivitet
Påvirkning på relasjoner	<p>22. Sett utenfra; Oppfatter du at dynamikken mellom bruker og ektefelle blitt påvirket av avstandsoppfølgingen? Eventuelt på hvilken måte</p>	<ul style="list-style-type: none"> • Grunnlag for samtale og diskusjon • grunnlag for konflikt og irritasjon • knyttet til målinger/prosesser – morsrolle eller helt motsatt: • Frustrasjon over teknologien • Mindre konflikt, noen andre som følger opp partner. • grunnlag for felles prosjekt • blitt nænere i relasjonen • Endringer i partners motivasjon gjennom A.O. som påvirker deg

Appendix 3 - Information letters and consent forms

A) Sample I – Older Spouses



Informasjonsskriv

Dette skrivet gir informasjon om formålet med prosjektet du er spurt om å delta i og hva din deltakelse i prosjektet vil bestå av.

Jeg er mastergradsstudent ved Oslo Met (tidl. Høyskolen i Oslo) og studien du er spurt om å delta i er knyttet til min masteroppgave som skal utføres mellom august 2018 og mai 2019.

Det overordnede temaet for masteroppgaven er velferdsteknologi for eldre, og mer spesifikt skal studien utforske *hvordan det er å være eldre pårørende under den velferdsteknologiske tjenesten 'medisinsk avstandsoppfølging'*.

Formål med prosjektet

Medisinsk avstandsoppfølging er en av flere velferdsteknologiske satsingsområder i Norge. Hvordan brukerne selv opplever denne tjenesten er det gjort flere undersøkelser på, men det er i midlertid mindre kunnskap om hvordan brukernes nærstående og pårørende opplever denne formen for velferdsteknologi.

Formålet med dette prosjektet er å utforske hvordan det er å være eldre pårørende under den velferdsteknologiske tjenesten 'medisinsk avstandsoppfølging'. Jeg søker med denne studien å belyse hvilken rolle de pårørende får under denne formen for velferdsteknologi og hvordan de selv påvirkes av denne formen for tjeneste. Påvirkning på trygghet, mestring/kontroll, livskvalitet og relasjoner er aktuelle tema her.

Hvorfor blir du spurt om å delta?

Du blir spurt om å delta fordi du er ektefelle/partner/samboer til en som er bruker av og som mottar den velferdsteknologiske tjenesten 'medisinsk avstandsoppfølging'. Jeg vil gjerne gjennomføre et intervju med deg om dine erfaringer og tanker knyttet til temaene i studien. Jeg planlegger å gjennomføre intervjuer med mellom 6 og 10 pårørende i denne studien.

Hva betyr deltakelsen for deg?

Dersom du velger å delta i prosjektet vil du bli intervjuet av meg. Intervjuet vil ta om lag en time og spørsmålene vil være knyttet til hvordan du som pårørende til en som følges opp gjennom medisinsk avstandsoppfølging opplever din rolle knyttet til denne tjenesten, og hvordan du påvirkes av denne tjenesten. Intervjuene vil bli tatt opp på med en lydopptaker, men lydopptakene vil bli slettet etter at de er transkribert.

Deltakelsen er frivillig.

Det er frivillig å delta og man kan trekke seg så lenge studien pågår uten å oppgi grunn og uten at det vil ha noen konsekvenser.

Ansvarlig for studien.

Jeg vil som masterstudent ved Oslo Met være den som utfører studien i dette prosjektet. Prosjektet veiledes av Jardar Sørvoll, som er forsker ved NOVA. Kontaktdetaljer til oss begge finner du i slutten av dette informasjonsskrivet.

Behandling av data, personvern og dine rettigheter

Det lovlige grunnlaget for behandlingen av personopplysninger i prosjektet er ditt samtykke.

Opplysningene som oppbevares vil ikke kunne knyttes til ditt navn eller andre opplysninger som gjør det mulig å identifisere deg direkte. Det er kun meg selv og veileder som har tilgang til informasjonen som er gitt inn i studien og all informasjon vil bli behandlet og lagret på en trygg og konfidensiell måte.

Du har rett til innsyn i personopplysninger som blir registrert, samt rette eller slette disse etter eget ønske. Du har også rett på en kopi av dine personopplysninger og klagerett til Datatilsynet eller NSD (personverntjenester@nsd.no eller telefon 55 58 21 17)

Hvem kan jeg kontakte?

Dersom du har spørsmål om undersøkelsen eller ønsker å benytte deg av dine rettigheter kan du kontakte:

Student og utfører av studien:

Solveig Bryne Castberg Stølan. E-post: s976323@oslomet.no. Tel: 48 19 37 83

Veileder for masteroppgaven og forsker ved Nova:

Jardar Sørvoll. E-post: jarso@oslomet.no. Tel: 93 22 43 05

OsloMets personvernombud:

Ingrid Jacobsen, ingridj@oslomet.no. Tel: 99 30 23 16

Med vennlig hilsen

Solveig BC Stølan, Mastergradsstudent
OsloMet

Jardar Sørvoll, Veileder
NOVA



Samtykkeerklæring

Jeg har mottatt og forstått informasjonen om prosjektet *'om å være en eldre pårørende i den velferdsteknologiske tjenesten 'medisinsk avstandsoppfølging'* og jeg har blitt gitt mulighet til å stille spørsmål knyttet til denne.

Jeg gir samtykke til:

Delta i et intervju som en del av dette masteroppgave-prosjektet

At mine personlige data kan behandles frem til avslutningen av prosjektet, medio mai 2019.

Signatur/Dato

B) Sample II – Health Care Professionals



Informasjonsskriv

«Medisinsk avstandsoppfølging: Rollen til og påvirkningen på eldre pårørende».

Dette skrivet gir informasjon om formålet med prosjektet du er spurt om å delta i og hva din deltakelse i prosjektet vil bestå av.

Jeg er mastergradsstudent ved Oslo Met (tidl. Høgskolen i Oslo) og studien du er spurt om å delta i er knyttet til min masteroppgave, som skal utføres mellom august 2018 og mai 2019.

Formål med prosjektet

Medisinsk avstandsoppfølging er en av flere velferdsteknologiske satsinger i Norge. Hvordan brukerne selv opplever denne tjenesten er det gjort flere undersøkelser på, men det er mindre kunnskap om hvordan brukernes pårørende og nærstående opplever denne formen for velferdsteknologi.

Formålet med dette prosjektet er å belyse hvordan det er å være eldre pårørende når ektefelle/partner følges opp gjennom '**medisinsk avstandsoppfølging**'. Studien søker å utforske hvilken rolle de pårørende får under denne formen for velferdsteknologi og hvordan de selv påvirkes av denne velferdsteknologiske tjenesten. Trygghet, mestring/kontroll, frihet, aktivitet og relasjoner er aktuelle tema her.

Hvorfor blir du spurt om å delta?

Du blir spurt om å delta fordi du gjennom ditt arbeid er bidrar til gjennomføring av den velferdsteknologiske tjenesten '**medisinsk avstandsoppfølging**', og gjennom dette kan ha kjennskap og perspektiver på hvordan de pårørende påvirkes av denne tjenesten. Jeg vil gjerne gjennomføre et intervju med deg om dine erfaringer og tanker knyttet til temaene i studien. Jeg planlegger å gjennomføre intervjuer med inntil 10 pårørende, samt intervjuer av et lite antall nøkkelpersoner i kommunehelsetjenestene, som en del av denne studien.

Hva betyr deltakelsen for deg?

Dersom du velger å delta i prosjektet vil du bli intervjuet av meg. Intervjuet vil ta om lag en time og spørsmålene vil være knyttet til hvordan du, som sentral i tjenesten '**medisinsk avstandsoppfølging**', oppfatter de pårørendes rolle knyttet til tjenesten, og hvordan pårørende påvirkes av denne tjenesten.

Vi finner en tid og et sted for intervjuet som passer for deg. Intervjuene vil bli tatt opp på med en lydopptaker, men lydopptakene vil bli slettet etter at de er transkribert.

Deltakelsen er frivillig.

Det er frivillig å delta. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ansvarlig for studien.

Jeg vil som masterstudent ved Oslo Met være den som utfører studien i dette prosjektet. Prosjektet veiledes av Jardar Sørvoll, som er forsker ved NOVA. Kontaktdetaljer til oss begge finner du i slutten av dette informasjonsskrivet.

Behandling av data, personvern og dine rettigheter

Det lovlige grunnlaget for behandlingen av personopplysninger i prosjektet er ditt samtykke. På oppdrag fra Oslo Met har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket. Opplysningene og informasjonen som oppbevares vil ikke kunne knyttes til ditt navn eller andre opplysninger som gjør det mulig å identifisere deg direkte. Navnet og kontaktopplysningene dine vil jeg erstatte med en kode som lagres på egen navneliste adskilt fra øvrige data.

Det er kun meg selv og veileder som har tilgang til informasjonen som er gitt inn i studien. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Du har rett til innsyn i personopplysninger som blir registrert, samt rette eller slette disse etter eget ønske. Du har også rett på en kopi av dine personopplysninger og klagerett til Datatilsynet eller NSD (personverntjenester@nsd.no eller telefon 55 58 21 17)

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Prosjektet skal etter planen avsluttes i mai 2019. Dine opplysninger, lydopptak og transkriberinger destrueres i sin helhet når prosjektet er ferdig.

Hvem kan jeg kontakte?

Dersom du har spørsmål om undersøkelsen eller ønsker å benytte deg av rettighetene som er beskrevet over kan du kontakte:

Student og utfører av studien:

Solveig Bryne Castberg Stølan. E-post: s976323@oslomet.no. Tel: 48 19 37 83

Veileder for masteroppgaven og forsker ved Nova:

Jardar Sørvoll. E-post: jarso@oslomet.no. Tel: 93 22 43 05

Personvernombud ved OsloMet:

Ingrid Jacobsen, ingridj@oslomet.no. Tel: 99 30 23 16

Med vennlig hilsen

Solveig BC Stølan, Mastergradsstudent, OsloMet



Samtykkeerklæring

Jeg har mottatt og forstått informasjonen om prosjektet «*Medisinsk avstandsoppfølging: Rollen til og påvirkningen på eldre pårørende*» og jeg har blitt gitt mulighet til å stille spørsmål knyttet til denne.

Jeg gir samtykke til:

Delta i et intervju som en del av dette masteroppgave-prosjektet

At mine personlige opplysninger kan behandles frem til avslutningen av prosjektet, mai 2019.

Signatur/Dato

C) Information letter to the Sample I participants' partner

Informasjonsskriv til ektefelle/partner

Om deltakelse i studien

«Medisinsk avstandsoppfølging: Rollen til og påvirkningen på eldre pårørende».

Dette skrevet gir informasjon om formålet med prosjektet din ektefelle/partner er spurt om å delta i og hva deltakelsen i prosjektet vil bestå av.

Ansvarlig for studien.

Jeg er mastergradsstudent ved Oslo Met (tidl. Høyskolen i Oslo) og studien er knyttet til min masteroppgave, som skal utføres mellom august 2018 og mai 2019. Jeg vil som masterstudent ved Oslo Met være den som utfører studien i dette prosjektet. Prosjektet veiledes av Jardar Sørvoll, som er forsker ved NOVA. Kontaktdetaljer til oss begge finner du i slutten av dette informasjonsskrivet.

Formål med prosjektet

Medisinsk avstandsoppfølging er en av flere velferdsteknologiske satsinger i Norge. Hvordan brukerne selv opplever denne tjenesten er det gjort flere undersøkelser på, men det er mindre kunnskap om hvordan brukernes pårørende og nærstående opplever denne formen for velferdsteknologi.

Formålet med dette prosjektet er å belyse hvordan det er å være eldre pårørende når ektefelle/samboer/partner følges opp gjennom 'medisinsk avstandsoppfølging' og studien søker å utforske hvilken rolle de pårørende får under denne formen for velferdsteknologi og hvordan de selv påvirkes av denne velferdsteknologiske tjenesten.

Hva går din partners deltakelse i studien ut på?

Dersom din partner/ektefelle velger å delta i prosjektet vil han/hun bli intervjuet av meg.

Spørsmålene vil være knyttet til hvordan han/hun, som pårørende opplever sin rolle under tjenesten medisinsk avstandsoppfølging, og hvordan han/hun som nærstående påvirkes av denne tjenesten. Rolle, ansvar og kompetanse, trygghet, mestring, kontroll og påvirkning på relasjonen er aktuelle tema for studien.

Intervjuene vil bli tatt opp på med en lydopptaker, men lydopptakene vil bli slettet etter at de er transkribert. Det er frivillig å delta, og din partner kan når som helst trekke sitt samtykke til å delta tilbake uten å oppgi noen grunn.

Hvorfor mottar du dette informasjonsskrivet?

Du mottar dette informasjonsskrivet fordi du som ektefelle/partner kan identifiseres indirekte ved å være ektefelle til den pårørende som intervjues, ditt navn kan også komme frem i intervjusituasjonen, samt at det kan det komme frem sensitive opplysninger om helseforhold i denne settingen.

Behandling av data og personvern

Siden det er din ektefelle som er i fokus i denne studien og opplysningene vi innhenter om deg er få, vil vi ikke innhente samtykke fra deg. Du har likevel rettigheter etter loven. Det lovlige grunnlaget for å behandle personopplysninger om deg er et lovgrunnlag som heter allmennhetens interesse. På oppdrag fra Oslo Met har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Opplysningene og informasjonen som oppbevares vil ikke kunne knyttes til navn eller andre opplysninger som gjør det mulig å identifisere din ektefelle/partner eller deg indirekte. Navn og kontaktopplysningene vil erstattes med en kode som lagres på egen navneliste adskilt fra øvrige data. Det er kun meg selv og veileder som har

tilgang til informasjonen som er gitt inn i studien. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

Dersom du ønsker, har du anledning til å protestere mot at personopplysningene dine blir behandlet.

Du har rett til innsyn i personopplysninger som blir registrert, samt rette eller slette disse etter eget ønske. Du har også rett på en kopi av dine personopplysninger og klagerett til Datatilsynet eller NSD (personverntjenester@nsd.no eller telefon 55 58 21 17)

Hva skjer med opplysningene når vi avslutter forskningsprosjektet?

Prosjektet skal etter planen avsluttes i mai 2019. Alle personopplysninger, lydopptak og transkriberinger vil destrueres når prosjektet er ferdig.

Hvem kan jeg kontakte?

Dersom du har spørsmål om undersøkelsen eller ønsker å benytte til rett til å protestere kan du kontakte:

Student og utfører av studien:

Solveig Bryne Castberg Stølan. E-post: s976323@oslomet.no. Tel: 48 19 37 83

Veileder for masteroppgaven og forsker ved Nova:

Jardar Sørvoll. E-post: jarso@oslomet.no. Tel: 93 22 43 05

Personvernombud ved OsloMet:

Ingrid Jacobsen, ingridj@oslomet.no. Tel: 99 30 23 16

Med vennlig hilsen

Solveig BC Stølan, Mastergradsstudent, OsloMet

Appendix 4 – NSD Approvals

A) NSD approval 30 October 2018

NSD Personvern

30.10.2018 10:29

Det innsendte meldeskjemaet med referansekode 199770 er nå vurdert av NSD.

Følgende vurdering er gitt:

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 30.10.18, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD ENDRINGER

Dersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringer gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET

Prosjektet vil behandle særlige kategorier om helseforhold og alminnelige av personopplysninger frem til 15.05.2019.

LOVLIG GRUNNLAG FOR DEN PÅRØRENDE

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 og 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a.

LOVLIG GRUNNLAG FOR TREDJEPERSON/EKTEFELLEN

Prosjektet vil behandle særlige kategorier av personopplysninger om tredjeperson med grunnlag i at oppgaven er nødvendig for formål knyttet til vitenskapelig eller historisk forskning. Behandlingen har hjemmelsgrunnlag i personvernforordningen art. 6 nr. 1 bokstav e), jf. art. 9 nr. 2 bokstav j)), jf. personopplysningsloven §§ 8 og 9.

PERSONVERNPRINSIPPER

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

DE PÅRØRENDES RETTIGHETER

Så lenge de registrerte (den pårørende) kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20). NSD vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13. Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

TREDJEPERSONERS/EKTEFELLENS RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13/14), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning

(art. 19) og rett til protest (art. 21). NSD vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 14. Vi minner om at hvis en tredjeperson tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32). For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og/eller rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET

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

Lykke til med prosjektet!

Kontaktperson hos NSD: Belinda Gloppen Helle Tlf. Personverntjenester: 55 58 21 17 (tast 1

B) Approval 8 January 2019 – Additional Sample

NSD Personvern

08.01.2019 10:08

Det innsendte meldeskjemaet med referansekode 199770 er nå vurdert av NSD.

Følgende vurdering er gitt:

Vi viser til endring registrert hos NSD 07.01.2019. Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 08.01.2019. Behandlingen kan fortsette.

DE ANSATTES TAUSHETSPLIKT

NSD minner om at de ansatte i kommunen har taushetsplikt. Det er derfor viktig at intervjuene gjennomføres slik at det ikke samles inn opplysninger som kan identifisere enkeltpasienter, pårørende eller avsløre taushetsbelagt informasjon. Vi anbefaler at dere er spesielt oppmerksom på at ikke bare navn, men også identifiserende bakgrunnsopplysninger må utelates, som for eksempel alder, kjønn, sted, diagnoser og eventuelle spesielle hendelser. Vi forutsetter også at dere er forsiktig ved å bruke eksempler under intervjuene.

OPPFØLGING AV PROSJEKTET

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

Lykke til videre med prosjektet!

Kontaktperson hos NSD:

Belinda Gloppen Helle

Tlf. Personverntjenester: 55 58 21 17 (tast 1)