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Security when Caring for Cancer Patients at Home at the End of Life

- Interviews with the Bereaved in the County of Sogn og Fjordane

Master's thesis in Clinical Health Science - Pain and Palliative Care

Supervisor: Anne-Tove Brenne and Beate André

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Acknowledgments

The experiences and thoughts of family caregivers of seriously ill and dying patients have interested me for a long time. I have had the impression that this group is often overlooked and not focused on in an already tough phase of life. To be able to help improve the services and set the focus on caregivers' rights is important and rewarding to me both as a healthcare professional and as a human being. Being able to contribute to a better and safer palliative course for the caregivers through better interaction and communication between healthcare professionals, healthcare services and caregivers is important and meaningful.

To produce a master thesis like this has been a long, and sometimes tough process, but it has given me the opportunity to talk to the carers of deceased cancer patients in my own county, Sogn og Fjordane. By this, I have been able to examine the factors that give them the security to be able to carry out home care. This will give me, my colleagues and other healthcare professionals in Sogn og Fjordane valuable information that can help improve and ease palliative care and thus the caregivers' experience in this life-changing and difficult phase.

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Abstract

Background: In the last decades it has been most common to die in hospitals or in nursing homes in Norway. However, cancer patients wish to stay longer at home and maybe die at home. Still, Norway is on the bottom of the list of home deaths in Europe. An important factor that determines the patient's and family's choice and wishes to stay at home and die at home is the feeling of security and safety when caring for the patient at home. Carers play a crucial role in the facilitation of time at home and home death, and it is important that they feel secure in their task to be able to carry out home care. **Purpose:** The overall aim of this study was to explore factors that determined the security of family carers of patients with advanced cancer who cared for the patients at home in Sogn og Fjordane. **Material and methods:** A qualitative study using semi-structured in-depth interviews with bereaved with experience from caring for cancer patients at home at the end of life was performed. **Results:** Three main categories emerged from the analysis; "Personal factors", "Healthcare professionals" and "Organization" of healthcare. **Conclusion:** Several personal factors contributed to the feeling of security among carers of cancer patients caring for the patient at home at the end of life. However, healthcare professionals and the organization of healthcare service contributed most to the feeling of security. This suggests the need to ensure good competence in palliative care among healthcare professionals caring for patients with advanced cancer at home and well-organized palliative care services with defined responsibilities to provide security to carers caring for advanced cancer patients at home at the end of life in the county of Sogn og Fjordane.

Relevance

With an increasing number and age of cancer patients in many countries, there is an increased need for family caregivers. Carers are an important part of the treatment and care of the palliative cancer patient. They may have to safeguard the interests of the patient because he or she is unable to convey information themselves or have knowledge about the patient which can be important in the treatment. Illness among a family member affects the carer substantially; from being able to sustain a social connection to experiencing physical pain. Contributing to the carer's security in the palliative phase is important to be able to carry out home care. By strengthening the factors identified in this study, the carers' overall feeling of security is improved. This may also be strengthening for the carers in the time after the death of the patient. The results may be applicable for areas outside the county of Sogn og Fjordane with similar challenges in palliative healthcare services as in Sogn og Fjordane.

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1. Background

1.1 Introduction

To be cared for, and to die at home is important to many patients and family caregivers (from here called carers) (1). Being in their habitual surroundings with what is known and loved can be of great significance to both the patient and their carers. It can provide room for reflection of the life that has been and the time that awaits while preserving the best quality of life possible (2-4).

A Norwegian study shows that a total of 55 percent of people with advanced cancer reported that they wanted to die at home (5). In a Danish study, 54 percent of patients with advanced cancer reported that they wanted to die at home (6). International studies claim that >50% percent want to stay at home as long as possible (7). Still, Norway is on the bottom of the list of home deaths in Europe, both for cancer patients and non-cancer patients (8, 9).

Many people want to die at home, but to care for a patient at home is a considerable burden and leads to insecurity for carers (7, 10). There are much research and evidence that the carers experience physical, psychological, social and financial challenges, and many are not prepared for the demands and challenges they may encounter (11). Lack of focus on carers own needs from healthcare professionals may lead to poor mental health and low quality of life (12).

Carers are often the patients' most important support, and in most situations, a resource (13). They know the patient well and have the experience of how to help the individual. Many of them exert significant responsibility- and care tasks to their loved ones and take therefore a central part of the total care resource given by our society (13-15).

A systematic review and thematic synthesis of qualitative evidence from 2015 that included 18 studies from countries all over the world revealed both positive and negative perspectives and experiences of caregiving at home (16). Support from healthcare services and healthcare professionals was repeatedly said to be of great importance to carers, providing security to enable home care. Carers reported difficulties when they were unprepared for, or no longer could handle, home care. They reported that when they had little choice but to fulfil home care, with little or no communication about their own needs and preferences, caregiving was a big strain. Failures in carers' informal and formal support networks increased the difficulties surrounding care at home (16).

Norwegian research shows that carers experience that their needs of support and help are not recognized nor taken seriously by the healthcare service and that it is difficult to get personalized help for the needs they have as a family (17). Palliative care is a central part of cancer care, and death is an unavoidable endpoint. Carers can be insecure and uncomfortable with what to say, what to do or how to approach in care for the terminal patient, and thereby how to master the situation themselves (18). They often look to healthcare professionals for guidance and expertise. Therefore, the feeling of security from healthcare providers and services, among other things, is an important feature for carers who are coping with palliative care at home with the insecurities, challenges, needs, and care-burden they face daily (19, 20).

Sogn og Fjordane county in Norway is a large county of more than 18 000 km² and with around 110 000 residents divided into 26 municipalities. The county has two local hospitals and one Central Hospital. The county's only palliative care team, as well as the oncology and hematology departments and the physicians responsible for the cancer treatment, are located at Førde central hospital in the middle of the county. One of the longest drives from a municipality in Sogn og Fjordane to the central hospital in Førde is three and a half hours (21). The county is characterized by fjords, mountains, and islands and has many bad roads with great danger of avalanche, which often results in closed roads. Some municipalities are small, on the mainland and have a short distance to the local hospital or have several nursing homes. Other municipalities are large, consist of several islands, and people may have to take a ferry or a boat to their destination, which also is dependable on the weather, or generally have a long travelling route. All of this is affecting access to healthcare services.

Two studies conducted in Canada in 2010, found that the likelihood of receiving professional palliative care at home was significantly lower for persons in rural/remote locations (22, 23). The challenges experienced in rural/remote regions, by receiving little palliative care and long journeys to health services led to increased likelihood of admission to an institution compared with urban residents (22, 23).

The overall aim of this study was to explore factors that determined the security of family carers of patients with advanced cancer in Sogn og Fjordane that cared for the patient at home. Increased knowledge about these factors will be of value when planning improvements of palliative care in Sogn og Fjordane.

The following research question will be addressed:

- What factors made the relatives feel secure when they cared for the patient with advanced cancer at home in the county of Sogn og Fjordane?
 - In the case that the patient died at home- what facilitated home death?
 - In the case that the patient did not die at home- what were the barriers for home death?

1.2 Theoretical Background

1.2.1 Deaths in Norway

In 2017 there were 40 678 deaths in Norway, 10 894 of these died of cancer where 75% of them were over 60 years old (24, 25). For the first time in Norway, more people died of cancer this year than from cardiovascular disease (10 370), making cancer the most frequent cause of death (26). Of all deaths this year, about 12 324 (30%) died in hospitals, while 21 129 (52%) died in nursing-care homes. Only 5 095 (13%) people died at home (25). Fewer people die at home today than 30 years ago (13% vs 18,3%) (8). Increasing age and the epidemiological shift represented by changes in medical disorders can explain much of this change (8).

1.2.2 Aim of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (27).

Palliative care includes both treatment and care. It has a focus to maintain or improve quality of life and therefore becomes different from the treatment that has a focus on curative treatment (28). Palliative care applies to all healthcare professionals who work with severely ill and dying patients, regardless field of study, level of treatment or level of care. Palliative care attends to ensure the assessment of symptoms and afflictions, symptom relief, information to patients and their relatives, safeguarding of the relatives, terminal care, grief counselling and follow- up of bereaved. It also ensures documentation and communication between the different actors. Palliative treatment and care do not hasten death nor postpone the death process but sees death as a part of life (29).

It is recommended internationally and nationally that palliative care must enter the patient's course as soon as a life-limiting diagnosis is given, and that palliative care is not only integrated into the specialist healthcare services but also in primary care (29, 30). Despite the geographical and volumetric differences between the municipalities and hospitals, the principles are the same in integrating palliative care (31).

1.2.3 Challenges in Palliative Care

Palliative care is a medical field that goes far back in time from before the second world war when the doctors had few curative treatments to offer patients. Today we have countless treatment options with early diagnosis, new medication and the possibility of individual adaptation. This has led to more patients living longer with their disease, but also as a result of incidence trends, more people die of cancer. Many of these patients may need palliative care at the same time as they receive life-prolonging treatment (32).

The combination of increasing incidence and longer and more complicated life-prolonging treatment causes increased pressure on healthcare services. The necessity of cooperation increases and becomes clearer (28). Patients with the need for palliative care exist in all parts of the healthcare service. They will alternately need general physicians, municipal healthcare services and more specialized healthcare services. The patients' medical history is often complex and the challenges that the patient and their relatives meet are therefore also complex (31).

The coordination reform which was introduced in 2012 says that seriously ill and terminal patients shall be met with a qualitative and comprehensive offer close to home (33). For the patient to stay at home as long as possible and maybe even die at home, it is important that relatives feel competent and confident in the tasks that accompany. To achieve a good course, healthcare professionals must have enough knowledge, competence and a close and predictable relationship with the relatives where involvement and good communication are crucial (31, 34). This causes higher requirements of knowledge about palliative care among healthcare professionals (31).

1.2.4 Organization of Cancer- and Palliative Care in Norway in General and in the County of Sogn og Fjordane in Particular

Palliative care takes place within most areas of the healthcare system in Norway and is provided in both specialist healthcare and in the municipal health- and care services (29). The different levels of care both contribute in providing the best possible healthcare. Basic palliative care is

to be carried out everywhere where seriously ill and dying are cared for, and healthcare services shall also accommodate with a special, organized, palliative service at all levels (29).

Home nursing care and nursing homes give the patients the opportunity to stay longer at home, or even die at home or in their home municipality. Central actors for good palliative care in the municipalities are general practitioners, doctors at the nursing homes, home care nurses and other healthcare professionals involved in care (29).

Sogn og Fjordane has an ambulant interdisciplinary palliative care team that works with counselling and follow-up of patients with terminal illnesses and their families. The cancer ward at Førde central hospital has three available beds for palliative care. These beds are part of the palliative center and served by the palliative care team. The team is stationed at Førde central hospital and is affiliated with the cancer ward. The team works all around the hospital where it is needed and cooperates with the other two hospitals and the institutions in the municipalities (35). When required, the palliative care team travels and meets colleagues or the patient and their families in the municipalities.

There are beds earmarked for palliative care in 17 municipalities in Sogn og Fjordane (35).

For palliative competence to be distributed throughout the county, a network has been developed of resource nurses in cancer and palliative care in Sogn og Fjordane. The cooperation is formally anchored through an agreement between Helse Førde and the municipalities. There are among a hundred nurses in this network, distributed in all municipalities and hospitals in the county. Several of these nurses have additional education in cancer and/or palliative care. A resource nurse works near the patient and with competence building through internal teaching and system development in their own workplace. The goal is that the patient and the family can experience professional quality in the care services, no matter in which municipality they live. The network is operated by the Regional Centre of Excellence for Palliative Care of the Health Region West (36).

In Sogn og Fjordane there are eight cancer coordinators, covering 12 municipalities. A cancer coordinator works in close cooperation with patients, relatives and colleagues in the municipalities. The offer is a "low threshold" offer that does not require referral. The cancer coordinators are educated cancer nurses and coordinate and facilitate the provision of health services and -offers in everyday life for the cancer patients and their relatives and they are a link between specialist and municipal health services. It is a national goal that all municipalities should have their own cancer coordinator (29, 31, 35).

1.2.5 The Importance of Family Carers in Caring for Advanced Cancer Patients at Home
Carers are an important and central group for palliative efforts as it is formulated in WHO's definition of palliative care (27). Palliative care also includes carers' quality of life in the phase of life-threatening illness among a family member (27). To ease the tasks of caregiving for carers, we need to know and understand what may be helpful during this phase (37).

The carers are the people that the patients report as his/her carers. If the patient is unable to specify who this is, the carers are the one(s) who has permanently and continuous contact with the patient (38). They are an important resource for the seriously ill and dying patient. They represent safety and security and are persons the ill trust. The carers can help take care of the patient's own integrity and self-image through disease and treatment. They have known the patient over a longer period and can provide important information to healthcare professionals (29, 37, 39).

1.2.6 Carers' Insecurity when Caring for Advanced Cancer Patients

Life-threatening illnesses like cancer do not only affect the ill, but also the family, friends, and colleagues (40, 41). The threat that a family member is expected to die in the nearest future will often change the family structure. Normal patterns that are incorporated in the family culture may become dysfunctional, the ability to unite and the ability to manage negative feelings are set to the test (39, 42).

The carers make a significant effort for the patients and thus constitute a resource for society (39, 43). Many treatment options are today decentralized, and tumor-directed treatment can be given in the municipality and at home. To try to make the patient's life the best possible, the carers often take time off from work or reduce work hours. They often also put own hobbies or activities and social life aside. The carers contribute with emotional support and practical help like transport, administration of medicine and care and at the same time take over the patients' previous tasks (44). This makes them exert a greater resource than before (44). Many patients react positively to this support, but they can also be concerned that a too big of a burden is put on the carers (20, 39). In this situation, the carers are putting their own need for support and relaxation aside. This can lead to an overload (20, 39).

To provide care and support to others has many positive aspects (40, 45). Regardless of professional care and whether the patient is at home or not, it can be experienced positive, meaningful and satisfactorily to help. Caring for someone can contribute to a greater feeling of proximity. It can also give a feeling of coping and meaning (40). However, being the carer at

the end of life can cause considerable physical and psychological stress and strain and may contribute to different challenges and dilemmas. Carers become a bearer of their own worries, the patient's worry, and they must handle challenges the disease brings with it. This may lead to exhaustion, anxiety, stress, fatigue, isolation, depression and sleep problems (11, 46). They may have to take tough decisions and can experience lack of time because of the extra tasks, feeling of loneliness, loss of control, insecurity and worry about the future. The lack of time many experiences can give a feeling of inadequacy, and they can feel that they do not have time for others they care for. This is likely to contribute to a lower quality of life (37, 39, 42, 47).

Decreasing stay in hospitals, more use of outpatient treatment, long course of illness, more time at home and maybe home death cause the carers to experience that much of the responsibility is put on them (31, 37, 39). To care for the ill and dying patient at home with changes of the home-structure, invading and refurbishing of the home and involvement of different actors like homecare, cancer coordinator, physiotherapist, and general physician, can lead to insecurity. This responsibility and the situation itself can represent a significant strain (3, 44). At the same time, these actors make it possible for the patient to stay home and receive as good treatment and care as possible (3).

From the year 2010 to 2060 it is expected a doubling of Norwegians that are 67 years old or older (48, 49). A gradually aging population and increasing occurrence of cancer, dementia and lung- diseases, implies that more and more people will live with a seriously ill person in their family. Many carers will have a relatively high age with accompanying risk themselves of having a decreased health function (26, 50).

1.2.7 Security in Providing Home Care

Patients and their families have different preferences for care and treatment and have a need to be heard, but common for all is that the choices the individual patient and family make, will depend on what feels safe for them (43, 51, 52). Where to be cared for at the end of life and where to die are the last important choices a human being makes, and how the patient and relatives are met by healthcare providers, is crucial for the experience of care (52, 53).

Many carers want to contribute to care even if they do not have any earlier experience with this (29). Information about the disease, treatment and expected development are therefore important to receive for them in order to be able to contribute, as long as the patient agrees (29, 38). In addition to this, it is important that they know about their own rights in the care of an ill and dying person. This emphasizes the need for interdisciplinary cooperation between other

professionals like a social worker, physiotherapist, occupational therapist, psychologist, chaplain and dietician, in addition to doctors and nurses (31, 33). The closest carers should be invited to conversations with healthcare professionals as early as possible (29). Often there will be a need for several conversations with the patient and conversations with the carers alone. The advantage of an early conversation with the whole family and give them the opportunity to ask questions is that the patient and the relatives together remember more of the information that is given (13, 29). Carers' need for information is often persistent present and increases near the end, although the patient is less interested in information about the disease, prognosis and treatment at the end of life (39).

Planning of time at home and home care must be done with cooperation between municipal services, hospital and the carers. It is important to pay attention to the whole family when planning time at home for the patient. Conditions at home, carers' resources and needs should be assessed before discharge from hospital to home. It is important that healthcare professionals have knowledge and competence to see if or when the insecurities in care tasks become too big of a strain for the carers (31, 34, 39).

Taking care of the carer's own needs will reduce the insecurity in the period of the disease, the palliative phase and after death with the grieving process that follows (29, 37). It is also positive that carers and healthcare professionals have established a relation when the patient's life is close to the end and the difficult message is given that life-prolonging treatment must be terminated or that death is approaching (39, 54). Care and protection of the carers will indirectly be of help for the patient (37). Engaging them in decisions about care and treatment of the patient may have a positive effect on how they will cope, master and experience stress and grief in the post- mortem period (29, 37).

2. Materials and Method

2.1 Study Design

This is a qualitative study using semi-structured in-depth interviews with bereaved with experience from caring for cancer patients at home. In each family, one or two family members were interviewed. Only one interview was conducted per family, so in case more than one family member wanted to take part, they were interviewed together. This was because, in one family, several family members may have shared the task of being carers. This can facilitate a discussion between the carers to get different and complete views of the care tasks, caring for the palliative cancer patient at home.

A qualitative interview seeks to understand and reveal the importance of peoples' experiences and understandings of the world (55). This design was chosen because qualitative in-depth interviews focus on the bereaved carers' descriptions and reflections of his/her experiences with home care; home death or institutional death, planned or unplanned, as well as how the bereaved experience communication, information, follow-up and access to health services in the decision or preference of the place of death (55, 56). This brings forth diversity and nuanced descriptions through the interviewer's active listening to what the bereaved tell (57).

2.2 Participants

Family carers of deceased cancer patients were recruited from different municipalities in Sogn og Fjordane. By including carers from several municipalities, one was able to obtain variation in the informants' and patients' distance, access, offer and travel time to the nearest health service.

Since most of the cancer treatment is given at Førde central hospital in the middle of the county, it was most likely that the deceased cancer patients had received much of their treatment here, and that both the patient and the carers had a close relationship with this hospital and the healthcare staff there. It was therefore desirable that carers also were recruited at different distances from the central hospital.

When the goal is to seek a deeper understanding, a few informants may be sufficient (58). 8-10 participants were considered sufficient to be able to study carers' experiences and the need for information and follow-up in such a process. This is also a feasible number to recruit and interview in Sogn og Fjordane for a master thesis.

2.3 Recruitment Process

Recruitment was conducted as follows:

1. After receiving a guide (Appendix 1, Appendix 2) containing information about the study and how to approach potential participants, cancer coordinator/nurse in the home municipality of the patient/carer approached the potential informant, informed about the study and asked if they were willing to be contacted by the master student.
2. The cancer coordinator/nurse provided written information about the study and a consent form to the informants (Appendix 3).
3. The master student received contact information from cancer coordinators/nurses about the family carers if the potential participants gave their acceptance. They were then contacted by the master student a few days later. They then received more verbal

information and got the opportunity to ask questions. The master student would at this point ask if the family carers accepted to participate in the study.

4. Interviews were scheduled and conducted continuously as the relatives agreed to participate in the study.

There was not planned any follow-up of the participants other than the contact they already had with their cancer coordinator/nurse. However, the participants had the opportunity to contact the master student after the interview.

2.4 Inclusion Criteria

Inclusion criteria were the following:

- Parents, children or spouse of a deceased cancer patient (all ≥ 18 years of age)
- Previous or current contact with cancer coordinator/nurse or palliative care team in Sogn og Fjordane.
- Carers of patients who did not permanently live in an institution
- Ability to understand questions and disseminate information in Norwegian or English
- Provision of written informed consent
- Between 2 and 12 months since the loss of the family member
- Experience of home death or institutional death of cancer patients, planned or unplanned

It was desirable with approximately equal distribution of gender, but this was determined by the availability of the sample population. It was also desirable that there was recruited approximately equal distribution with experience from home death and from institutional death, but this was also determined by the availability of the sample population.

2.5 Data Collection and Management

Ten municipalities and the palliative care team were contacted for recruitment of participants about six months before the start of the study. It was planned that each municipality recruited one or two informants.

2.5.1 The Interviews

The carers and the master student scheduled a meeting for an interview in a suitable room /office in their home municipality, or where it was most convenient for the carer.

Interviews were audio- recorded after consent from the informant. Audio-recordings facilitated the transcript to ensure the quality of information. Before the audio-recordings of the interview

started, the master student explained the content and implementation of the interview to the informant.

Interviews were conducted using a semi-structured interview guide (Appendix 4), compiled by the study supervisors together with the master student. The questions in the interview guide focused on the carers' experiences and thoughts from caring for the family member and the experiences and interaction with healthcare services. The first questions were open and formulated so that the participant was to tell in general about his/her experiences with being a carer, while gradually the questions became more focused on specific topics related to the research questions (56, 59).

During the interview it was taken notes about the non- verbal communication the informant expressed and written keywords about what was said. This facilitated that it could be asked further questions about words, expressions, and topics and thus receive a deeper understanding of what the informants conveyed. The master student sometimes had to reconsider or omit questions in the interview guide because the questions were not relevant or because the interviewee already had answered this question earlier. The interview guide was therefore not always followed to the letter (59).

2.5.2 Collection of Study Participants' Characteristics

Age, gender, socioeconomic status, place of death (home or institution), if the patient had analgesia pump, time of death and time of cancer diagnosis of the deceased family member, and age, gender, socioeconomic status, residence (lived with the deceased or not) and relationship to the deceased of the carer was registered (Appendix 5).

2.5.3 Transcription and Data Analysis

The audio-recorded interviews were transcribed verbatim by the master student. All interviews were transcribed word by word, and every short or long breaks or interruptions were marked. Laughter and cry were written down and laughterful or crying speech was marked with signs around the sentence. Emphasized words were marked with a sign. Unclear speech or sentences were also marked. All the interviews were transcribed in Norwegian Nynorsk as they were performed in this language. As there are many different dialects in this county and there are few inhabitants in each of the municipalities, the dialect was not reproduced in the transcript to ensure anonymity. Names of place or persons were changed or omitted. The transcript was read through a second time and improved.

The qualitative data analysis software Nvivo 12 pro was used to import, manage and analyse the interviews (60). When the researcher codes, he/she reads through the transcription and condensate and code relevant paragraphs. Nvivo 12 pro allows the researcher to retrieve coded paragraphs for reinvestigation and recode or combine different codes into categories (60).

Natural units from the transcribed interviews were condensed into meaning units. Then, codes were extracted from the meaning units. Coding of transcription forces the researcher to get to know every detail of the material and provides an overview that may be useful (61). The codes were divided into categories that no longer were associated with the interview guide. The codes were referenced with the informant's ID so that it could be traced back to the empirical data (61).

Further, subcategories were identified under each category. In this process, subcategories with themes not included in the original interview guide came up.

Table 1 Examples of natural units, meaning units, code, categories and subcategories

Natural units	Meaning units	Code	Categories	Subcategory
<i>We had no experience in our family with cancer, so it was completely new and therefore I wished that they were a bit more direct, so that I had realized how the situation was</i>	(Direct) information from healthcare professionals are important for the feeling of security for carers	Factors contributing to a feeling of security for carers	Healthcare professionals	Information
<i>I think it was the right decision. To see how he enjoyed himself at home, he got to play music and he got to stay in the living room, and- he enjoyed himself when he got home.</i>	To be at home helps normalize everyday life and gives a feeling of freedom	Factors contributing to home death	Personal factors	Attitudes towards the place of care and place of death

2.6 Confirmability and Trustworthiness

One way to ensure the confirmability of the material is to use two or more persons to read the transcript (62). Two of the interviews were randomly selected and sent to the master student's two supervisors for reading and analysis to ensure that the interviews were analysed approximately the same way. This increases the trustworthiness of the results to the informants' voice. Seven of the transcribed interviews were read and analysed by the master student alone. Trustworthiness was also ensured by going through the transcribed interviews several times (62).

The design of the interview guide was made with the intention of not having any leading questions but focused openly and entirely on the bereaved carers' thoughts and experiences. The questions were also formulated and designed to answer large aspects of the study questions in the master thesis. Therefore, the design contributed to deep and thorough answers to the study questions.

The researcher of this master's thesis is an educated nurse that has worked with cancer patients in Sogn og Fjordane in Norway, both in primary care and in the specialist health service. She has for several years observed the questions and uncertainties that arise among carers when their close ones no longer are offered curative treatment and are at the end of life. When the researcher has knowledge and experience with cancer and palliative care, one will have a good understanding of the factors researched. The experiences the researcher has within the environment provide an understanding and recognition of what the informants convey (62).

2.7 Ethical Issues

The master thesis protocol was approved by the Norwegian Centre for Research Data (NSD) ref.nr 61366 AMS/LR before starting the project (Appendix 6).

Study participation was voluntary, and the informants had to sign a written consent form before the start of the interview (Appendix 3). Consent forms were handed out when they were informed about the study from healthcare professionals, as this was the most practical approach due to the geographical distance from the master student to the potential participants.

A list that connected the participants' names and study-ID were stored in a locked cabinet that only the master student had access to. The audio-recorded interviews were stored in a password-protected computer. When transcribing the interviews, all identifying characteristics were changed. All demographic and disease-related information was given by the informant in a separate form (Appendix 5) before the start of the interview, thus, no medical records were

used. This form was marked with the informant's study- ID. All information about the informants during all parts of the study were treated with confidentiality.

Data material will be destroyed when the work on the study is completed, by the latest 30.06.2019. The results are only used anonymously for presentation for health professionals and in scientific publications. If the informants wanted to withdraw from the study during or after the interview, all data would be deleted and not included in the study.

2.8 Time Schedule

	2018								2019					
Month:	5	6	7	8	9	10	11	12	1	2	3	4	5	6
Finalization of protocol														
Application to NSD														
Inclusion and interview														
Transcription and analysis														
Writing the Master Thesis														
Exam														

2.9 Budget

Travel expenses for participating in interviews were refunded after the submission of the travel bill. Expenses were refunded by NTNU. No informants travelled for implementation of the interviews and there were therefore no expenses for the informants.

3. Results

3.1 The Informants

A total of five cancer coordinators/nurses from five municipalities contributed to the recruitment process. Altogether, 11 bereaved carers were contacted by the master student, one refused to participate. Ten bereaved carers from nine families were recruited and gave their written consent to participate, and nine interviews were conducted. Eight interviews were individual, and one interview was with two informants from the same family. Six out of ten pre-contacted municipalities had no relevant informants; therefore, one additional municipality

was contacted to achieve the desired number of informants. One to three informants were recruited from each municipality. No informants were recruited from the palliative care team.

Seven of the interviews were conducted in the informants' home as this was their wish. One interview was conducted in the informants' workplace while another interview was conducted at a local café at the request of the informant. The informants had distance between 115 km and one km to Førde central hospital.

Each interview lasted from 63 to 180 minutes. People in a phase of grieving are vulnerable and therefore it takes time to get started with the interview. The interview that lasted 180 minutes was the one conducted with two informants.

When the analysis process began, one found that it was useful in the work with the results that it was mapped who of the families had contact with the palliative care team. This was originally not asked for in the question form (Appendix 5) but was brought up in all the interviews and registered in the table of the informant's and the patient's characteristics.

Characteristics of the informants and the patients are given in table 2 and 3.

Table 2. Demographic characteristics of the informants

N= 10

Age mean (range)	60,5 (41-76 years)
Sex	
Female <i>N (%)</i>	10 (100%)
Male <i>N (%)</i>	0
Highest accomplished education	
Primary School <i>N (%)</i>	0
High School <i>N (%)</i>	5 (50%)
College/University <i>N (%)</i>	5 (50%)
Living situation	
Lived in the same residence as the diseased <i>N (%)</i>	5 (50%)
Lived in another residence than the diseased <i>N (%)</i>	5 (50%)
Relationship to the diseased	
Spouse/cohabitant <i>N (%)</i>	5 (50%)
Child <i>N (%)</i>	4 (40%)
Parent <i>N (%)</i>	1 (10%)

Table 3. Demographic and disease-related characteristics of the deceased

N=9

Age mean (range)	72,9 (49-86 years)
Sex	
Female N (%)	2 (22%)
Male N (%)	7 (78%)
Highest accomplished education	
Primary School N (%)	1 (11%)
High School N (%)	5 (56%)
College/University N (%)	3 (33%)
Years cancer-diagnosis mean (range)	4,6 years (4 months- 18 years)
Subcutaneous analgesia pump N (%)	6 (67%)
Months since death to interview mean (range)	7,5 months (3-12 months)
Place of death	
Home N (%)	3 (33%)
Hospital N (%)	3 (33%)
Nursing Home N (%)	3 (33%)
Contact with the palliative care team N (%)	8 (89%)

3.2 Presentation of Results

The final results concluded with three main categories with associated four or five subcategories presented in table 4.

Table 4. Overview of categories and subcategories

Categories	Personal factors	Health care professionals	Organization
Subcategories	Presence	Competence and Knowledge	Healthcare Service
	Attitudes towards the Place of Care and the Place of Death	Roles and Responsibilities	Equipment
	To be more than One Carer	Information	NAV
	To Talk about Death	Language	Attendance Allowance
	To have a Driver's License	Palliative Care Team, Cancer Coordinator and General Practitioner (GP)	

3.2.1 Personal Factors

3.2.1.1 Presence

To be present and to follow the patient in the palliative phase was a matter of course and pointed out as important by the informants. They felt good conscience and safety when they were able to be near the patient, spend all the remaining time together and when they knew that the patient never was alone. Some said that they would not leave the patient alone because they never knew when it was over. They felt this because the informants themselves did not want to experience to die alone but to have family and loved ones around. However, to be present all the time could sometimes be experienced as tiring.

It was important for me to be with him... to be there, all the time. And it wasn't hard, it was natural to be there. It was safe for me to be there with him (Informant 6).

I didn't manage to combine it with work, even though I worked quite close and could ride a bike both ways, I never knew when he could call and when he needed help and- I walked around on my tip toes all the time. So, then I chose to quit my job. (...) I think I had regretted it today, if I didn't quit and hadn't had the time for him (the patient) (...) So, for me, it was important that I was able to be present all the time (Informant 8).

3.2.1.2 Attitudes towards the Place of Care and the Place of Death

The most repeated reason for what led to home death was that it was the patient's desire to die at home. For the patient, it was experienced, as told by the informants, as secure and good to be at home with the familiar smells, surroundings and to still feel like a part of the family and have family around. The informants said that it was important that the patient got to fulfil his/her last wishes, and very often, these wishes were dependent on the attendance of carers. The conscience, love and care they had for the patient made the carers go a long way to achieve this even though it affected their own physical health, mental health or social life.

I knew he wanted me there, and that he became safe because of this and calmed down. But really, I feel I went into some kind of vacuum. I went on autopilot, I did what I was asked for, what was expected of me... I do not know how I did it (...) I was unsure of a lot, and it was very stressful, certainly. But knowing that he felt safe, that was the most important thing for me (Informant 5).

Some informants felt safe when they could care for the patient at home, in a familiar place, instead of spending time in an unknown or foreign place where they had to adapt to other's premises. They wanted to do as much as possible themselves, without so much help from

healthcare professionals (HCP). This had a lot to do with the fact that it helped normalize everyday life. They could, to a greater extent, plan the day themselves and felt more like a whole family without having HPC around all the time.

It was also said that when they were at home, it was easier for neighbours, friends or other family members to visit the patient: one could stop by when it suited them, they could make food when they wanted, and if they were in need for a rest they could lay down at a bed or a sofa. It was often several people at home which facilitated to good conversations and getting a break from the role of being a carer. Also, one got to have meaningful conversations with the patient without interruption from HCP. It was therefore also experienced socially to be at home. Especially important was that the informants' children, the patients' grandchildren, could come and go as they wanted, without being limited by visiting- hours at an institution and at the same time being spared from seeing other ill people. Then they could focus on the person they knew and not on other peoples' destinies or illnesses. This gave the informants fewer worries and therefore contributed to a feeling of more calmness, relaxation, and security to be at home.

At a hospital, it was said to be a different pace, focus, and atmosphere. It was experienced exhausting for both the patient and the informant. The rooms were small, making them feel that it was no room for them to be. At a quadruple room, the patient and the informant got a corner of the room, with even less space, where the only distinction from other patients was a curtain. Other patients could easily hear what the informant and patient were talking about, and they could hear other patients' conversations with HCP or relatives. It was said that this was fine and could even be experienced as socially talking to other patients when the patient was healthier, but not in the palliative phase. Some informants said that they felt like they were in the way or that their things were in the way and that it was no place to retreat. At home, it was experienced as more room and gave a greater feeling of freedom which contributed to the feeling of security.

(...) because it is completely different traffic in hospitals, and noise and- it's tiring. (...) something had to be measured, something- blood tests or temperature or blood pressure or something... and if they were two-three patients in the room, then there was a lot of traffic (Informant 6).

However, if the patient's situation was complicated with many issues and depending on many measures, there were some informants who felt greater security when the patient was admitted to an institution with HCP around all the time. The reason for this was composed of several

factors: they were tired after caring for the patient at home for a long time, the patient got an infection or other complications, they did not feel they had the competence to care for the patient and/or that they did not feel that the competence in the municipality was good enough to care for the patient at home. The informants felt they had to monitor the patient all the time when HCP were not there, which affected carers' sleep quality. Some of the informants that had experienced home death said that if the patient had lived longer than they did, they would have had to "give up" and let the patient be admitted to an institution due to the physical and psychological strain that often gradually became worse. This gave a feeling of extreme exhaustion and/or they felt that they did not manage to provide proper care for the patient at home anymore.

She couldn't have done it without my help (care for the patient at home). To be alone hadn't worked. It was at night and everything- you have to sleep sometime too. No, it was tough (Informant 1).

*It was good that he died when he died. If he had been fourteen days or longer, at home, he might have become worse and got a new infection and fever or something- if he couldn't be at home, that he **had** to get admitted at the hospital, than he would probably never come home again. So, for him, who wanted to die at home, it meant a lot (Informant 4).*

(...) He wanted to be at home, but it didn't work. He had so much tubing and drains and analgesic pump and epidural in his back and- (...) Yeah, I hadn't the competence to manage that (Informant 3).

There were many common denominators to be at an institution at the end of life. Some said they preferred hospitals to be the place of care because they felt that the HCP had more specialized knowledge and competence in the area and therefore felt more secure by handing over the responsibility there. Having spent a lot of time in hospital made the informants feel like they knew the HCP that worked there, which made it easier to ask about things and they felt more secure. However, some felt that there was no room for a dying person in a hospital, as it was a greater focus on curative treatment, and felt a lack of calmness. Therefore, some informants preferred nursing homes to be the place for the end of life. In some cases, this was the patient's own desire. The informants thought this was because the patient would not turn the home into an institution and would not put the responsibility on their carers. Other times this

happened in the absence of communication about the possibilities of dying at home, or that the informants themselves did not feel they had the capacity to care for the patient at home.

Those who had experienced to be in nursing homes highlighted the calmness that was experienced there. The families lived in the room designed for palliative and dying patients, emphasizing that they felt a greater peace, more space for them to be and it was a much «homelier» environment there than in a hospital. The HCP was also highlighted as much calmer than the HCP in hospitals. The care of the patient was done at a different pace, and the informants felt greater security and care for themselves. They felt that the HCP had more time for them.

Many of the informants said it was important that the patient got to come home to the home municipality to die, regardless if this was the home, nursing home or local hospital. This was most often because of proximity to family and friends and familiar surroundings.

3.2.1.3 To be more than One Carer

To be more than one carer was said to be very important for the feeling of security. It was a relief when one could share the responsibility and discuss decisions that had to be taken regarding the patient and that others saw what the informant went through and what was required of him/her without them having to say it. It was also said that it was easier to make decisions regarding the informants' own health, for example when they needed a break, when they got support from others, even though most of them wanted to be present with the patient.

*(...) I declined the offer of attendance allowance; this I wanted another sister to take. This had something to do with that I didn't want to be alone in this (follow the patient in the last phase). I wanted more people to be involved because I had-... *sigh* I had been doing this alone for so long (Informant 5).*

*(...) It's exhausting to be healthy at the hospital. So, I had to build myself up again on hiking- trips, that was my medicine. (...) This was a high priority of mine. I got good support from my physiotherapist to do this, so that made it a little easier to do *laughter*. It's something about that, it wasn't just me who said it (that it was tough), but it was others who understood the problem (Informant 8).*

3.2.1.4 To Talk about Death

To be able to be open and realistic about the remaining time and that death was approaching was said to be difficult, but important for the family concerned. It contributed to a feeling of

security for the informants, knowing what the patient wanted and thought about death approaching and that they did the right thing in relation to the patient's wishes. It was not important to talk about religion and the spiritual regarding death, but more the practical issues around the patient and what he/she wanted for the remaining time and afterward.

Practical

The informants emphasized the importance of fulfilling the last wishes of the dying patient. This was also the case for wishes after the patient's death, with family gatherings and funeral. Several expressed the fear of making mistakes in relation to the desire of the dying. Topics that were repeated were: Where does he/she want to be in the last phase? Does the dying want to be cremated or buried? Does he/she want a big or small funeral? Does he/she want the funeral to end at the grave, or to have a memorial service afterward? Who does he/she want to be present at the funeral?

It was important for me to do what was right for him. I can't bear the thought of sitting here and think afterward that maybe I did something wrong - maybe he wanted something else. So, it was very important to me that I- Therefore, I had to talk to him about different things. I had to... (Informant 6)

Feelings

The informants said that this was an important topic to talk about. Several of the informants said that they were afraid to address this topic in fear of hurting the patient's feelings. Some were afraid that the patient had not accepted the fact that he/she was dying, because they never talked about death approaching. Some were also afraid that because they did not talk about it, it was not said or talked about things that one wanted to say or talk about before it was too late and did not have the chance to say goodbye to each other, making the informants insecure in the situation. Several of the informants said it had been easier to talk about death if HCPs had brought it up.

*(...) But then- he (the patient) got very good contact with the one doctor, and he opened up for her (the doctor). (...) Then we talked together all three of us and I think that was easier for **him** (talking to HCP) plus that I got to know what- I did not need to go and wonder what he was thinking about (Informant 4).*

I tried to hint, but I was so scared that it would be misunderstood, that he would think I would get rid of him or something, or that he would understand something else than what I really meant (Informant 8).

One informant said that she or the patient would not talk about this topic, not between themselves nor with HCP. Information about palliative and terminal care or death was said not to be necessary, rather contributing to uncertainty. This informant expressed it as ‘why wait for things to happen when it may not happen?’ when she was offered a conversation about signs of death approaching.

3.2.1.5 To have a Driver’s License

Informants settled around the county said that they were used to the distances and had adapted to this, even though some said that the commuting to and from the hospital when the patient was admitted, could be tiring. However, what was common for most of the informants and which was emphasized as a very important factor for security was that they had a driver’s license. This meant that they had easier access to healthcare services and equally important: they could easier have a break and concentrate on their own health and needs.

It wasn’t just a safety (that she had a driver’s license), it was of great help because then I could come and go whenever I wanted to. Plus, then- I travelled often to my son because- it wasn’t always easy to come home to an empty house. You may have a need to be with others. So, that I have the driver’s license was essential (Informant 4).

One informant who lived close to the central hospital said that the short distance to healthcare and healthcare professionals was a very important factor.

The times he needed medical help, it was- not decisive, but it was of great security (that they had a short way to the hospital) (Informant 7).

3.2.2 Healthcare Professionals

The need for good healthcare services (HCS) and helpful healthcare professionals (HCP) was most often said to contribute to the feeling of security and constituted most of the interviews conducted.

3.2.2.1 Competence and Knowledge

The informants felt safe when the HCP had the knowledge to see if the patient was in pain or in other ways was unwell and could provide medication or other measures to ease the situation. It was also said to be important that they were supportive and took concerns, questions and messages from the carers seriously and was able to help them themselves or contact other HCP that could help or give advice.

I'm very impressed with all these skilled nurses, I have to say. They worked hard, they were always smiling and helpful and- that was very positive. Knowledgeable and- It's a little safe and good to know that you are being taken care of and taken seriously (Informant 8).

It was substantial that the HCP did not only confront and saw the patient but also talked to the informants, so they felt seen in this phase. Some informants expected to be included more than they were when the home nursing care came visiting. Several of the informants expressed a need for talking to the HCP when they stopped by because they had spent most of the day alone with the patient. They had therefore different questions and were sometimes in need of confirmation that what they were doing was right. Some of the HCPs met these needs, but this was often dependable on the individual HCP.

(...) They (home nursing care) didn't ask, they just went straight to the room. Didn't ask how the night had been, very little dialogue with my mother (...) The work she did with cleaning his wounds two hours of the day and care and food and following him to the toilet and- all the time, all day (...) They didn't care about her. She needed care. Someone to talk to. Someone to discuss medication with, that asked how the night had been and how the medication should be throughout the day, how much morphine we should administer- we couldn't do that when it came unskilled persons (Informant 1).

Informants described that they had different experiences with home nursing care. They felt safer when HCP with more experience or more education in palliative care or cancer care than if someone with less experience in the field came. Many of the informants' bragged about the individual HCP. Helpfulness, compassion, knowledge, competence and that he/she also included the carer was said to be important.

(...) but we had someone that was very skilled, so when they came, my dad lit up and smiled and it felt so secure and good. So, obviously- when the person that had the competence and were educated cancer nurses and could- it was like night and day. Then my mom and I could relax and knew that he was in good hands. It was so good. And then we got information afterward, and advice and-... (Informant 1).

3.2.2.2 Roles and Responsibilities

The informants felt that caring for the ill person at home carried a lot of responsibilities. Some felt like they had to monitor the patient all the time because they were afraid that HCP would overlook something or not see changes when they were visiting. This led to less trust in HCP

and a high level of stress, exhaustion and insecurity, and less energy and concentration in the need of just being with the patient. The informants said that if HCP took over some of the tasks, they felt safer and could again concentrate on what was most important to them: having the role as a family member.

(...) she was very enthusiastic when they came (home nursing care). It felt safe and secure for us to know that they were visiting her. But when there were changes, they were slow. And in that phase of changing, it's very tough to be carers, because you see things, feel things and know things, and the rest (HCP) doesn't follow (...) it wasn't clear between us (carers and HCP) what kind of responsibilities- (...) at the same time, it isn't our responsibility (to clarify and distribute the responsibilities) (Informant 2).

3.2.2.3 Information

The lack of information, unclear information, and information that was given too late was said to be a big problem and contributed to a great deal of insecurity among the informants. The informants said that since they never had experienced going through such a phase before and were lacking knowledge about cancer, the patients' course or palliative care, they did not know what information they were missing or what to ask for in order to get the information they needed. This led to a considerable deal of uncertainty caring for the patient at home. Informants said that they had felt greater security if the information was given without them asking for it. They also wished that HCP were more direct about the information to the carers who never had been through a palliative phase before. However, many of the informants had good experiences with getting good answers and information from HCP when they asked.

*But it is like asking the right questions, knowing what to ask. What do you need to know? And you do not know this before you are in that situation, right? All the time it's something new you want answers to (...) It should have been a question they asked: whether one has experience with, or knowledge, about cancer. I tried to read of course, but it's **not** the same (Informant 8).*

Also, how the information was given was decisive. When the informants received brochures or other written information to read without HCP's explaining, they often did not read it because they felt that they did not have the time to read a brochure and/or that the information was not valid for them yet or that the information was given too late, which made the informants feel that HCP's were unrealistic to where the patient was in the phase of the disease or that the informants themselves denied accepting the outcome of the disease.

(...) the last days (of the patient's life) we got lots of brochures with much good advice in relation to what to talk about and- but then it was too late. They simply didn't pick up on the situation. Wow, I was not aware of everything that existed, which I could get better information about- about preparing for death in a way (Informant 1).

*The cancer coordinator came with these brochures... *laughter* about dying at home and everything and left them up there with my mother. I just took them away. Took them home with me, hid them. Like, "we shall not talk about this". So, my mom didn't get them until one or two days before (the patient's death) (Informant 5).*

Some of the carers expressed problems understanding the medical terminologies when the patient had received letters in the mail, or after admission, from the HCS. They did not feel that they received more information in these letters as they did not understand what it was saying.

The document he got after treatment: I wondered "what does this mean? What does it say?" Right? And they (HCP) may have explained a little bit, but you can't remember everything. It had been much better if they wrote things normal people understood, not these foreign words (Informant 8).

Medical words and expressions were also difficult when the carers were to pass on the information to the rest of the family. Others in the family, like the patient's children who may live far away, were dependent on what the main carer told them. Several informants wished that information was given not only to themselves but also to the rest of the family so they all had received the same information and could ask questions to the doctor directly and not get information through the main carer, something that contributed to an insecurity for the carer. The carers also expressed the need for meetings with HCP several times through the palliative phase, as they experienced not to remember everything that they were told in one single meeting.

It should have been an informative meeting much earlier, with the whole family. That is my greatest wish. (...) and not least for the children who never have had a meeting like this before, and just received information from mom and dad, who may say and perceive different things (Informant 8).

The lack of information about palliative care or the terminal phase was said to be of concern, especially when the patient was home a lot and they did not have daily contact with the specialist HCS. They said that information about what is normal in this last phase contributed to less

concern and greater security. It also came up that sometimes they missed that the HCP had more knowledge of death or were more open about death with the families.

All these changes, right? He was fine and well when he came home, ate and everything, and watching him from eating normally to that he doesn't want to eat, doesn't want to drink. It's a process. When you haven't been through it before, you don't know what it is. Now I know that it is normal, this is how it is when a body starts to collapse: you stop eating, you stop drinking. But, it's a concern obviously: "Oh my god, he doesn't eat anything" So, there could be more information on what changes to anticipate (Informant 5).

(...) I think most of the cancer patients think much more about death than we think (...) we should not be so afraid to talk about it (Informant 2).

Some of the informants claimed that they made uninformed decisions regarding the patient, such as taking the patient home to die. This led to insecurity caring for the patient at home.

(...) I didn't know what I went to. We didn't know that we took him home to die, right? We knew very little about what we did (...) we didn't know how much work it was going to be. The fact that it should always be someone with him, 24 hours a day, had not thought about the consequences of that at all (Informant 5).

Also, information about their own rights as carers was important and led to a feeling of security when caring for the patient at home. However, information about this was repeatedly said to be partially or completely missing. Some informants had not heard about these rights, such as attendance allowance.

*60 (days)?! (attendance allowance) No, I didn't hear anything about that. Did I have the right to 60 days? Yes, there you go (...) Then I could have been free of the sick leave *laughter*, and that was (...) 60 days? No, I got ten days. With pay, that is (...) I (eventually) quit my job (to be with the patient), but then I didn't get anything *laughter* (...) in retrospect, I think it is sad that I had to quit my job to be able to have a good conscience afterward (Informant 8).*

3.2.2.4 Language

To be able to understand what they were told by the HCP and felt that they were being understood was important for the feeling of security. Several informants said that it was uncomfortable, and they felt unsafe to be involved with HCP who did not master or

understood the Norwegian language. Poor language dissemination made the carers unsure of the HCP's knowledge and competence.

(...) if he said something, they answered "yes" no matter if they understood or not. So, both he and I felt terribly insecure (...) No matter what you said, you never knew if they understood what you meant (Informant 7).

3.2.2.5 Palliative Care Team, Cancer Coordinator and General Practitioner (GP)

Some of the informants felt more secure when the palliative care team took over the treatment and care of the patient. They did not only feel that the patient was in good hands, they felt that they got more understanding of their own worries and insecurities and felt cared for themselves as carers. They felt that services were more coordinated and that the team had more overview of the patients' course. The HCP in this team were experienced as easy to talk to. However, some of the informants mentioned that the weekends could be challenging and felt unsafe when the team was unavailable for contact. They also wished that the team came into the picture earlier in the palliative phase. Some of the patients had lived with incurable cancer for several years but had no contact with the palliative care team until the last months or days of life, making it harder to plan or coordinate the last phase of the patient's life. Some were also missing a closer contact between the palliative care team, the GP, home nursing care and the family.

(...) It was a shame that they were presented the last few days of mom's life (...) They should have been present earlier (...) They don't meet us (the family) at our best, the last few days (...) (Informant 2).

Yes, they (palliative care team) should have been present earlier. They explain things in a very good way, they have that experience. They were very good. They should have been present at the first information- meeting because then they could have supplemented the doctor... probably better (Informant 8).

Some of the informants had contact with the cancer coordinator in their municipality and said this contributed a great deal for them feeling secure in caring for the patient at home. However, some of the informants wished that the cancer coordinator was more present through the whole cancer phase so that they could get more detailed information about opportunities, rights and facilitation of the home and not only relate to the palliative care team and/or home nursing care.

Some of the informants did not have contact with the cancer coordinator and was not offered this either. These informants said they missed this and had thought that they were supposed to be offered more in the home municipality when the patient was at home.

It wasn't- we got a cancer nurse as a contact person, but it was never- I thought we should have had more like- I had thought we would have more follow-up in a way, but it was not offered anything like that. Not during the process either (Informant 1).

When the patient was at home, the GP was of great importance for the implementation and facilitation of care at home. To have continuous contact with an available GP that knew the patient and his/her medical history was said to contribute to great security. Some of the carers had received the private telephone number to the GP, saying that they could call at any time, which the carers presented as great security, even though they never used it.

3.2.3 Organization

3.2.3.1 Healthcare Services

According to informants, home nursing care was a significant resource and the most important help when the patient was at home. Many of the informants who had experience from care at home and/or home death said that they could not have managed without this service. Some had signed an agreement that home nursing care was to stop by on a regular basis and visit the patient when the carer was at work or had other errands. It was experienced secure to know that the home nursing care was around, and the carers had the opportunity to contact them whenever they needed to if it was just for a bed lift, this made the carers feel they got support and were not alone in the situation.

The most important was home nursing care (...). It was very difficult for him getting a comfortable position in bed-... and to be able to call them (home nursing care) and ask them to take those heavy lifts, it was worth gold (...) it was very important (Informant 5).

However, even though home nursing care was said to be one of the most important factors contributing to time at home and home death, it was considered as a burden and perceived as difficult to be involved with home nursing care when the carers experienced poor organization of the service. An aspect the informants said was the most difficult was the lack of continuity from home nursing care. It was exhausting to constantly deal with HCP that hadn't been there before, and the family had to be dependent on other people determining the day schedule. Also,

questions were raised about the exchange of information and the competence within the home nursing care system when staff without the competence to carry out measures were sent to advanced cancer patients.

The most bothersome is that it has been so many people to relate to. In the home nursing care. And I understand that they work shifts and it has to be like this (...). When you have ten days and ten different people, it's too much (...). I felt I spent much time informing the individual person who came in, about things and changes. And I wondered why it took so long before everyone was informed. That was something we said to them too, that they had to pass on these messages themselves, that we didn't have to give that information (Informant 5).

They came with different competence: everything from unskilled persons to nurses. It didn't seem like as it was considered what this patient needed of competence and continuity and what information they needed before they came into the home. Such an ill patient- I was very disappointed. But you have to understand: the ones who came did their best, right? It wasn't anything wrong with them, right? There was something wrong with the system (Informant 1).

Some families were unsure of how the home nursing care could help. Topics that emerged were: “what can they do that we can't do ourselves?” and they were uncertain about getting home nursing care involved and being dependent on this service since they no longer could plan their day themselves. It was also said that with home nursing care they never knew when someone could come and give painkillers or provide other important measures.

(...) we couldn't get a time when they came, so my father got very impatient. He didn't want to get up so early. We never knew. They could come between eight and ten in the morning, sometimes ten thirty. That is a long time to be waiting in bed (Informant 1).

(...) you couldn't ring a bell and get help when you needed to, it's not the same with home nursing care, right? They are on their rounds and there are large geographical areas and they can't get there so fast, so you feel much more alone. So, the insecurity with how we would get help when we needed it was- when could they come, right? (Informant 1).

Another factor that created a barrier of home care was that some municipalities still have home nursing care that cannot administer intravenous measures because of the lack of resources and/or competence. For one of the patients, this was a direct consequence that led the patient to wish to die at the hospital, and not at home as she would if she could get the help she needed.

She wanted to be home, but they (home nursing care) hadn't- she couldn't because they couldn't- (...)When she came home (from the hospital), she had to have intravenous pain relief, and then the home nursing care couldn't come home and administer this, so she had to go to the nursing home every day (...) That was the worst thing in this phase, that they can't- they knew that she didn't have long to live (Informant 9).

Good cooperation between the GP and home nursing care was said to be important for the implementation of home care and home death, especially when the home nursing care was much involved and the patient's condition changed frequently, for example with pain or dyspnoea. Knowing that they got help with this right away from the GP was of great security, instead of the home nursing care having to contact the hospital and maybe not get to talk to the responsible doctor before the next day or talk to an unknown doctor that did not know the patient. Some of the carers experienced that the GP left on holiday and there was no doctor who took over for the GP, as they were told, which made them unsafe and frustrated.

Another factor for the informants feeling secure in the implementation of care at home was that they had the opportunity to contact the hospital no matter what time of day if they had questions. The patients in these families had "open return" which meant that they could call directly to the hospital responsible for cancer treatment to get admitted, instead of having to contact the emergency room and talk to unknown doctors. It was also said that it always was easy access to an ambulance if needed, regardless of where they lived.

It was said that it was impossible to plan for time at home and/or home death in a short time because of all the actors that had to be involved. When unforeseen events occurred, the patient became acutely worse or that the patient was to be discharged from the hospital right before a weekend without a plan, care at home was not feasible.

3.2.3.2 Equipment

A major concern the informants had in terms of having the patient at home was the access to equipment. Receiving help from the HCP to get the necessary equipment in place at an early stage in the patient's palliative course was an important factor contributing to safety and

security. A patient who had installed a security alarm made the informant feel more secure if something was to happen when she was at work. Cooperation between HCP at the hospital and in the municipality was said to be important in facilitating home care and get the necessary equipment in place.

However, some of the informants said that they had to provide the equipment they needed themselves which was said to create a barrier and additional insecurity in the care for the patient at home.

*(...) I asked for equipment and different things, and then I got told that I could just get it myself: go to the nursing home and pick it up- I hadn't been to the nursing home in over 30 years *laughter*, so I didn't understand what they... were thinking about, that I was to go up there and ask for things for my father who was dying. I couldn't do that (...) I was supposed to pick up a uridom. Was I supposed to go and ask them for a uridom for my father? They couldn't know who I was! (Informant 1).*

3.2.3.3 The Norwegian Labour and Welfare Administration

To be involved with The Norwegian Labour and Welfare Administration (NAV) was repeatedly said to contribute to insecurity. Informants experienced resistance and slow processing time from this authority, which led to greater insecurity in the care of the patient at home and the informant's economic situation before and after the patient's death. Several of the informants said that this service was at no help at all.

*(...) there are many ways to occupy people *laughter*. "You can send a complain" "laughter". Yes, that's no problem, I can send a complaint, but then it takes more than three months before they deal with them, and then it is outdated. That happens in NAV. They protest and protest until it's been three months, and then it's too late. You can begin to wonder about this healthcare system of ours. This is the backside (Informant 8).*

(...) They (NAV) said that they had to have a confirmation that my husband really was so sick (...) It wasn't unfamiliar that he was sick, within the NAV- system, but this is the way it is. I haven't heard from NAV since. They wait until they don't have to pay. That's what happens (Informant 8).

3.2.3.4 Attendance Allowance

Although attendance allowance was said to be of good help when the informants had received information of this right, the system was said to be difficult and not adapted to today's cancer care or the carers everyday life. First of all, the system to apply for this was experienced difficult, second, it was said to be hard to plan in advance when they were to take out the attendance allowance.

(...) but it's a demanding system because you have to plan when to take out days and everything in that form, and you don't know that, because it's dependable on the health- both for my mother and my father- so, therefore, it was barely used (Informant 1).

*A: **That** is easy to say (planning distribution of attendance allowance), but in practice, it is not easy. Because I drove him to the central hospital one day, and then it was something- I was going home, then I suddenly got a phone call: no, they couldn't do anything with him (HCS), so I had to go back and pick him up and we had to wait until the next day. Imagine if I had agreed to work that day, right? (...) They have to make more flexible arrangements (...) I was struggling to make the days go around, had a big puzzle to get enough days (Informant 8).*

4. Discussion

4.1 Main Findings

According to the findings in this study, factors that contributed to security for the carers in care of the palliative cancer patient at home can be divided into three categories: "Personal factors", "Healthcare professionals" and "Organization". "Personal factors" are the family's or the informant's personal affairs which are important for contributing to security when being at home in the palliative phase. The category "Healthcare professionals" is about the importance of how HCP participate and appear in interaction with the families, the informants and other HCP, to provide security. The category "Organization" is about how the organization of the healthcare services can contribute to security in the care of the palliative cancer patient at home.

In this section, the main categories and subcategories from the results are discussed against previous research and the theoretical framework. Finally, strengths and limitations with the study and the method chosen will be discussed.

4.2 What Factors made Carers Feel Secure when they Cared for the Patient with Advanced Cancer at Home in the County of Sogn og Fjordane?

The result of this master thesis shows clearly that HCP and HCS are essential for the carers to feel secure in their task of caring for the patient at home. This is achieved by trusting that the HCS is provided by competent and knowledgeable HCP. This is consistent with earlier studies in other settings (19, 52, 63-65), and not surprising given that carers are often not used to care for severely ill patients and therefore have no previous knowledge about caring tasks, cancer or end-of-life care, which makes them dependent on HCP and HCS (63, 66). Trusting that the patient is receiving the help that is needed will contribute to the carers feeling calm and secure. Funk et al. (2009) found that competence and quality from HCP in care gave a sense of getting a break and eased the burden of caregiving (19). Therefore, it is necessary that HCP acquire the information, knowledge, and competence in palliative care needed to reduce some of the feelings of exhaustion for the carers and contribute to a feeling of security caring for the patient at home at the end of life.

One of the most evident findings contributing to the feeling of competent HCP, and thus security to be able to carry out home care, was HCP's ability to disseminate sufficient, relevant and timely information. Earlier research and this thesis have found that the carers received information because they asked for this themselves. Others have commented that they did not know what to ask about because they had not been through this before. This led to uninformed decisions (63, 67, 68). Today, there are numbers of medical drama television series and magazine- or newspaper articles. Therefore, the only information about home death and cancer many carers have may be what they have seen on TV or read in magazines. It is therefore understandable that the carers feel unsafe and unprepared for the role of caregiving when they are uninformed about what to expect or have an unrealistic expectation of care at home. It is important that HCP are direct and honest with information (54). The carers want to be aware of what happens and what is going to happen with their close ones (54). Several studies have found that adequate and timely information about the disease, the patient's course, everyday care and different rights for both the patient and the carer are important because it enables the patient and the family to make decisions about treatment as well as personal and social challenges (63, 64). It also influences how the carers cope and make them prepared for what they may encounter (63, 64). In contrast, it is shown that late information, the dissemination of information or the lack of information give the carers a feeling of uselessness, helplessness, insufficiency and a lack of control which again contributes to a great sense of insecurity (19, 63, 64, 66, 68, 69).

Thorsnes (2014) commented that carers experience the obtaining and shortage of information as a fight against the healthcare system (66). This expresses the need that HCP acknowledge the burden and the impact caregiving has on carers. This master thesis and the sum of studies show how important dissemination of information from HCS and HCP are. The carers are dependent on timely information about what is expected and what they are getting into to be able to make rational and safe decisions.

The informants in this master thesis expressed that it was important that the information given to the carers was communicated by HCP's that understood and mastered the Norwegian language. When nurses from foreign countries are asked to communicate orally and in written form in a non- native language, they may also lack knowledge of the norms and rules of the host nation (70). It is also uncertain of how well they can communicate and make clinical decisions. Then it may appear on the natives as if these nurses are incompetent and ignorant. The barrier of language can prevent skilful nurses from being understood by their patients and colleagues. This can affect the patients' and carer's safety (70). This highlights the importance of HCP that understand and can convey information in the Norwegian language when working in Norway.

To talk about the disease, prognosis, and death makes the carers more prepared for the end of life, the funeral and the time after death (54). To the informants in this master thesis, this contributed to more safety and security in decisions of the place of care, place of death and other decisions through the palliative phase and the time after death. Still, many are afraid of hurting the patient by addressing these topics (68, 71). Informants in this study suggested that HCP raised the topic regarding death. To talk about this as a part of the palliative course without the carers being the ones responsible for addressing this difficult topic is a measure that also appeared in other research (54, 68). Support from HCP regarding how to communicate these topics may also improve the relation between the carer and the patient (3, 54, 72). Death and the safeguarding of the carers in the palliative phase and in the bereavement period are central elements in palliative care (31). However, previous research and this master thesis have found that this is deficient in today's organization of palliative care (54, 68). Some of the informants in this study had the impression that HCP were afraid to talk about death and therefore contributed to a lack of information about this. When the patient was resistant to talk about death, it made the carers unsure and made it impossible to plan the remaining time in accordance with the patient's wishes. It also contributed to uncertainty about what the patient understood of his/her situation and how realistic he/she was. This may also have contributed to that the

patient did not retold important information he/she received from their doctor, to the carers. It can also make carers uncertain about their own perception of the situation. This can contribute to insecurity on how to care for the patient at home. Therefore, to carry out home care, it is important that the carers receive sufficient information about death and dying from HCP.

However, research has shown that different carers have different needs and cope with information in different ways (54, 68). This was also the findings in this master thesis. One of the informants expressed no desire to get information about palliative care and death at all. Therefore, knowing the exact time and way to provide information is not always clear. The valid evidence-based Carer Support Needs Assessment Tool (CSNAT) has been developed due to the lack of practical tools to evaluate and assess the carers' support needs in the palliative phase (73). This should be used frequently in assessing the individual carers' need for information and experience with caregiving and cancer. It is also important with regular conversations with HCP throughout the course of the disease and the palliative phase (67). This is necessary to be able to give continuous information if the situation changes from the expected palliative course. In addition, the involvement of carers in the care will also contribute to more information and give them security in their role of caregiving (74).

Norwegian law says that information about the patient's health condition and the provided healthcare is to be given to the closest relatives, who often is the carer, if the patient consents to it (38). Information distribution is therefore dependent on the patient. This is understandable and correct to safeguard the patient's privacy. There are many reasons why some family members should not have information about the patient's health condition. Still, HCS's and HCP's have a general duty of guidance to the carers (75). It is commonly known that carers need information, advice, and guidance from HCP to be able to care for the patient at home (63), and this does not require consent from the patient. However, the carers are often in need of more than general information and guidance when they care for the patient at home. This can be information about the patient's prognosis or special considerations that must be taken. If the carers do not get this information, it can affect their possibility to prepare for death and thus can make the experience of the palliative phase more difficult. For HCP, it is an ethical dilemma that important information cannot be given to the carers due to confidentiality and privacy towards the patient. The individual patient is complex and has individual needs. It is therefore difficult to provide general information when there is no such thing as the general patient. The duty of guidance may therefore be neglected because HCP's are afraid to break their duty of confidentiality. Therefore, to inform the patient and include the carer early in the disease

trajectory is important. If it is achieved a common understanding between the carer and patient, many carers will feel less insecure and have fewer worries and unanswered questions. This supports the use of advanced care planning (ACP), which involves the carers in addition to the patient, in interaction with HCP (74). It also shows a need for several conversations and meetings with HCP to be able to inform and prepare the carer and the patient for care at home and the end of life. It will depend on the individual family whether there will be a need for meetings with the carer and the patient together, or one or several meetings with the carer alone.

Even though the presence and involvement of HCP and closeness to the primary- and specialist HCS with their medical expertise made the carers feel more secure, it was equally important for the carers to be close to the patient themselves. This was especially important in the last palliative and terminal phase. Informants in a study of Blindheim et al. (2012) found that spending time together with the patient in this phase was helpful and led to greater closeness (67). This closeness was strengthening and meaningful for the carers (67). Carers want to be carers if this is the wish of the patient (63). The carers felt a responsibility giving back all love and care they earlier had received from the patient and this led to a joy and a rewarding feeling of following the patient through this phase (63, 76). This is said to make the bereavement period easier (76). It is therefore important to facilitate for the carers to be present with the patient as much as they want and highlights the importance that HCP support and acknowledge them in the care task.

Still, the uncertainty of the situation living close with a seriously ill patient is found to be physically, mentally and emotionally draining (19, 67). To have close family and friends in this phase gives the carers the possibility to share and discuss thoughts which gives a feeling of less loneliness and more security in making decisions both regarding the patient and regarding their own mental- and physical health (66, 67, 72, 77-79). However, even if emotional support from family and friends is important, it is not a substitute for support from HCP who have knowledge about the patient and the situation (54, 67, 71). It is important that HCP addresses them in the approach of the patient. The informants said that this does not require more than a greeting or a question about their well-being. This is supported in another research (54). This way they feel included, listened to, respected and acknowledged, making the care task feel easier. This is found to contribute to a feeling of security of being at home (19, 66, 67). Research has shown that the carers want to be seen as a part of the care team and want to learn more about caring for their relative in the best possible way (63, 67). To be involved as a part of the team give the carers a feeling of control in the situation, in addition to a feeling of participation, efficiency,

importance and security in caring for the patient at home (19, 63, 67). Røen et al. (2018) found that the carers felt like the HCP knew them better when they addressed them, and not only the patient (54). This made them feel safe and made it easier to ask questions (54). This indicates that the preferences and needs of emotional support should be talked about and assessed in conversations between HCP and carers early in the palliative phase. This emphasizes the use of the assessment tool CSNAT (73). In addition, findings in this thesis and in other studies emphasize the need for the HCP acknowledging and seeing the carer and involve them in care situations (54, 65-67, 72). HCP must also have the competence to distinguish between the carers' knowledge about the disease and their use of strategies to cope with the situation (67, 80).

Carers no longer had the role of just a spouse, child or parent, but also as the caregiver, transporter, medicine distributor and information provider. If the distribution of roles and responsibilities is unclear, the carers may feel that they are responsible for both the patient's personal and medical care and that they are to take on tasks and responsibilities that they have no training or competence to do. Linderholm et al. (2010) found that when the carers and HCP managed to build a relationship, the distribution of responsibilities between them became clearer, making them more secure in what roles the carer had and what the roles the HCP had (81). In addition, the carers experienced the HCP as more competent and knowledgeable when this was the case (81). It also was experienced that the HCP showed more care and that they were dedicated to their work (81). This emphasizes the importance of a clear distribution of roles and responsibilities between the carers and the HCP. This can be achieved by providing support and acknowledgment and to build a relationship with the carer. This may ease the burden and provide greater security for carers in the care of the advanced cancer patient at home in the final phase of life.

Even though the informants in this master thesis had mostly contact with HCP in the home nursing care when at home, some HCP with the special responsibility of palliative care was highlighted as important. The specialist palliative care team from Førde Central Hospital was said to have a great role in providing security. Earlier studies have shown that the availability of a specialist palliative care team, both physically and for telephone contact, is important for the feeling of security at home (53). The findings in this thesis show that the informants missed that the team had been involved earlier. The impression that HCP were afraid to talk about death, could be one of the reasons why the palliative care team was referred to, and involved, so late in the process. A study has shown that oncologists mainly refer patients with advanced

cancer to specialized palliative care services for physical symptom-related reasons, and not for other reasons like psychological or social issues (82). In addition, the oncologists in the study meant they were well trained to take care of the physical symptoms of these patients, something that led to an even later reference to specialized palliative care services (82). Carers may not have the knowledge or previous experience of cancer and life-prolonging treatment, and when HCP do not talk about this and the prospects either, the carers will lack information and thus reality orientation. Zimmerman et al. (2014) found that carers of patients with advanced cancer who received early palliative care (6-24 months before death) were more satisfied with care than those receiving only standard oncological care (83). Another study reported the same findings (84). These findings and the results in this master thesis support the need for early involvement from a specialist palliative care team and a more available team. These measures will depend on more knowledge and competence about palliative care among HCP, both in the specialist health service and in the municipalities. It will also depend on more offers of services in palliative care in the municipalities like an offer of local or municipal palliative care teams (31). Local palliative care teams in the county of Sogn og Fjordane may lead to less workload on the existing palliative care team in Førde Central Hospital and a better distribution of tasks between specialist care and community care (33). It may also give better availability of palliative care team due to smaller geographical coverage and less travel time, thus giving the carers and the patients a greater sense of security.

The GP has the main responsibility when the patient is at home, and the travel distance for the palliative care team is far, making them unavailable when palliative care is carried out at home. In this master thesis, the informants highlighted that contact with the GP was important for care at home. In a review of studies from America, Europe and Australia from 2018 it was highlighted by patients and carers that the availability of the GP was an important aspect of support to terminal patients (85). The GP could conduct home visits and be easily contacted, which was emphasized as important (85). However, carers expressed concern that the GP did not have sufficient knowledge about the disease, treatment or palliative care (3, 85). This underlines the importance of information acquisition, availability and more knowledge of palliative care among HCP, including the GP.

Cancer coordinators have a central role in contact with the patient and their carers (86). They assess, give emotional support and educate the patient and their family during their cancer treatment (86). Like the palliative care team, this coordinator has specialized competence and knowledge about cancer and palliative care (87). An important part of their job is

communication (87). However, many informants in this thesis said that they wished that these coordinators were more involved and more visible. This was related to the need for information about the possibility of facilitating home care and home death. This supports a need for cancer coordinators in each municipality. Even though Sogn og Fjordane have many resource nurses within cancer- and palliative care distributed throughout the county, they are not a substitute for cancer coordinators that have own positions allocated to cancer care. Like the proposals of measures with several palliative teams in the county, more cancer coordinators that cover every municipality in the county will better the accessibility of cancer coordinators and increase security for carers.

To be able to contact HCP any time of the day, whenever needed, was said to give a great sense of security. Research has shown that despite being alone with the patient, the carers do not feel like they are totally alone when there is always someone they can contact for support (19, 54, 64). Stajduhar et al. (2008) found that knowing that the carers were not alone in their situation and that they could always call for help was more important to some than having HCP present (64). This emphasizes the need to have contact information to HCP and HCS and have the opportunity to contact HCP whenever needed. It also highlights that the HCP that is contacted need to have the competence and knowledge about cancer, palliative care and the carers burden in caring for the palliative cancer patient at home.

Research has shown that timely and early planning of necessary equipment is a big part of the overall experience of home care and is an important component for the feeling of security (19). Without access to necessary equipment, carers are unable to keep the patient at home (19). However, the lack of information about different equipment and support in the home gave a feeling of uselessness and helplessness (63). In addition, if the informants in this master thesis previously had a negative experience with HCP, this was reinforced if they also were told to arrange the equipment themselves. In Sørhus et al. (2016) informants highlighted the need for different equipment and described great variations in how long it took before it was in place in the home and that it was stressful to have to arrange this themselves (3). These findings support the need for the carers to get help in obtaining the necessary equipment and that this facilitates care at home. Early planning and cooperation between hospital and municipality and a clear distribution of responsibility with an administrative person in the municipality, who can get the necessary equipment in place, may make this task easier for the carers (63). Carers may benefit from follow-up and support from the local cancer coordinator/nurse in regard to this (3, 54).

Distance to the Førde Central Hospital was not reported to be an important factor contributing to a feeling of security when caring for the cancer patient at home as first anticipated by the master student. Sogn og Fjordane has a challenging infrastructure and studies have shown that people living in rural/remote locations may have increased likelihood of admission to a hospital (22, 23). The informants in this master thesis had not thought of the distances to HCP and HCS as a problem. However, what was highlighted as being important, was having a driver's license. A study done in England in 2011 showed that distance was not a factor in the experience of hospital- accessibility (88). The same study from England showed that the experience of access to HCS was significant related to socioeconomic status, and thus car-ownership (88). Most of the informants in this master thesis had access to a private car which contributed to a feeling of security caring for the patient at home, knowing they more easily had access to healthcare. Many people are dependent on owning a private car in Sogn og Fjordane because of the long distances and fewer offers of public transportation than in urban areas. Sogn og Fjordane thus lies in the upper half of the ranking of registered cars in Norwegian counties (89). Equally important was access to an ambulance whenever needed, knowing they had fast and easy access to competent HCP in acute situations.

4.3 What Facilitated Home Death?

The informants' attitudes for being at home constituted a large part of the reason for home death. The most important reason for facilitating time at home and home death was the patient's desire. It is a goal that as many patients as possible get to live the last time of their lives in familiar surroundings (31). According to the informants, being together at home helped to normalize and make life naturally compared to admission to an institution and the patient could still feel like a part of the family, making it safe and secure being at home. Earlier research and this study showed that even though the informants sometimes experience problems with logistic, coordination, emotional reactions and practical task, it is experienced as meaningful and rewarding for the carers to be at home with the patient (3, 16, 65). At home, the carers have more freedom, they know where things are and there are no "uninvited" or strangers in their home (3, 72). They felt like "the master of own home". Caregiving at home has a positive impact, allowing the carers to demonstrate the love for their relative (16, 65, 68). Going through the illness trajectory is beneficial, making the families feel a greater sense of "togetherness" (16, 65, 68). Another positive aspect of home care was that the patient had the choice of company (65). He/she could spend more time with family and friends and separations were avoided (65). Like in this thesis, other studies have also found that it is easier for friends,

neighbours and other relatives to visit at home (65, 72). This is probably more important when the patient lives far from the central hospital, where admission will lead to the patient being far from family and friends.

Support from HCP and HCS was repeatedly described as being of great importance providing security for the carer and the patient when caring for the patient at home. Research has shown that this helps relieve carers which allow the patient to stay longer at home (16). Another study and this thesis found that many carers felt security knowing HCP came regularly (3). It was important that they could perform necessary measures and that they could contact competent HCP whenever needed (3). This highlights the need for competent and knowledgeable HCP within palliative care. It also supports a more available and predictable home nursing care to achieve more continuity and thus provide security for the families who are at home.

It was said that at a hospital there was a lack of space for the carers and it was another “traffic” than at home. If nurses and doctors have a lot of patients to take care of, it can be imagined that the carers and the patient do not feel seen or feel that HCP do not spend enough time with the individual patient or family that they feel is needed. The different patients are in different situations and have different conditions. This can mean that some of the roommates can be restless or confused, which leads to a lack of peace and quiet. There was generally a lack of privacy at a hospital, making the family wanting to be more at home. This is supported in another research where the carers’ felt a lack of time and busyness from HCP when admitted in hospital (68). Another study found that the hospital was often described as an unsuitable palliative care environment, where the reason for this often was said being its impersonal nature (16). The palliative phase and death are vulnerable and private phases in both the patient and the carer’s life. Having to share this with many strangers can feel like an invasion of privacy. This supports the need for a private space or a more suitable room or location for palliative care.

4.4 What were the Barriers for Home Death?

The most mentioned topic that made care at home difficult, even though this was an important factor facilitating home death, was about HCS and HCP. Some municipalities in Sogn og Fjordane still have HCS, especially home nursing care, that cannot offer different important measures, like subcutaneous pain relief or intravenous antibiotic treatment. There is therefore inequality within home nursing care between the municipalities in the county. Inadequate access to healthcare can give a sense of doubt, distrust and insecurity in regards to HCS and/or HCP (19). Even after the Coordination reform was introduced in Norway in 2012, where it is

said that all municipalities in Norway should manage more of the medical treatment closer to the patient's home and reduce admissions to hospital, there are still municipalities that do not have the resources or competence to offer simple treatment (33). This has by patients and informants in this master thesis led to mistrust in local HCS and HCP and have led to hospitalization in a lack of other opportunities, often because of situations that would have been handled at home if the patient had lived in another municipality.

Participants in Funk et al.'s study from 2009 expressed that even though access to home nursing care is important in the home environment and creates a feeling of security, it can also contribute to an insecurity of the personal and private space of the home and its normal routines (19). This was also expressed by informants in this master thesis. In two studies it is commented that the carers must manage the coordination of HCP and "retrain" each new worker who comes into the home and lose the ability to decide over different aspects of everyday life (3, 19). Similar findings had Stajduhar et al. (64). This emphasizes the need to be aware of that having home nursing care contributes to a sense of security in the sense of feeling supported but can also actually have adverse effects on the personal and spatial security of the home environment (19). These previous studies and the findings in this master thesis also support the need that HCP acquire information and exchange information among themselves about the patient and the disease before visiting the patient, by reading reports and charts, something that may reduce some of the burdens the carers are experiencing.

Carers are on one hand dependent on home nursing care to complete care at home. Conversely, if one is doubtful about the care provided by HCP, carers can lose faith in the quality of care and the advice they receive (19)

The informants in this study repeatedly mentioned episodes where they felt that HCP lacked information about the patient and/or had little knowledge and competence about cancer and palliative care. This is also in another article found to be experienced tiring and make carers feel insecure (65). In Sørhus et al. (2016)'s study, one informant said that it was best not getting help from home nursing care in the weekends because she was exhausted dealing with so many people and that it was nice not getting annoyed (3). Although many HCP's who wanted to help came into the informants' homes, they could not contribute when the HCP who came did not have the competence to carry out the measures the patient needed. This led to frustration and insecurity among the carers being at home with the patient. It is difficult to achieve continuity in a service that is characterized by working shifts, but findings in this master thesis and other studies support a clear need of more staff with the education, competence, and knowledge

needed to carry out measures in the home nursing care which may increase the feeling of security being at home. The provision of competent care is tied to trust in HCP.

Another difficulty described with home nursing care was help arriving late because of big geographical distances, for example when the patient needed rapid pain relief. This is also found by another study (71). Having to wait and a feeling of inadequate access can amplify a sense of insecurity about HCS and the individual HCP and can lead to stress for the patient and their carer (19). A hospital or nursing home is earlier found to be preferred because the institutions contribute to a feeling of safety and can give effective control of the patient's symptoms (90). This corresponds with the findings in this master thesis.

The lack of information about what home nursing care can offer can be a barrier for caring for the patient at home (19). Some informants had the feeling of lack of competence and knowledge among home nursing care because they did not know or were familiar with what home nursing care could offer. If the patient had a complicated illness and/or had drainages, analgesia pump or different catheters, one may have had the impression that the patient had to be at an institution with HCP around all the time to handle this even when this was not the case. Other research has found that carers may have taken on more responsibility or have performed more demanding care than necessary because they did not know what home nursing care could offer. They may also have lacked information about what equipment they needed that could contribute to making the care easier (63, 68, 71). Research has also found that the lack of information on what the home nursing care can offer can lead to a feeling of home nursing care taking over the family's life without any explanation as to what is being done or why it is done (19). This emphasizes the need for early and thorough information on what home nursing care can offer and information about the equipment available to facilitate the home for home care.

The patient and/or the carer may also have been determined to do as much as possible themselves, leading to the involvement of home nursing care late in the process, something that may have led the carers to take on all the care early and have become unnecessarily exhausted (71). Informants said that at home one could decide and plan their day themselves, something they could do to a greater extent when they were not dependent on HCS/HCP. If the patient also became much worse during the disease and therefore had poor mobility and was dependent on various medication and/or medical devices that the informants had to take responsibility of, this could lead to premature exhaustion and a feeling of unfeasibility which again led to having no surplus carrying out care at home.

Another barrier was that the carers themselves felt they were not able to have the daily responsibility of an advanced cancer patient who may have been dependent on much additional medical equipment and has felt this overwhelming. Carers may not have been used to, or would not take on, the responsibility of terminal care. As the findings in this master thesis, research has shown that carers express a fear leaving the patient, just to go in another room or floor in the house (63, 91). This was because they were afraid of what could meet them when they entered the patient's room again. They had a feeling of having to be vigilant all the time because they never knew what could happen or when the patient needed help. This can lead to both mental and physical exhaustion for the carers due to lack of sleep and physical exertion (91). Other studies have also found that because of daily tasks, carers have to leave the patient sometimes (63, 91). One article found also that carers did not want to show the patient that they were worried, sad or angry (63). This made them use different strategies to handle these emotional situations such as go into another room to "let the steam out" or lock the feelings in (63). This can make the balance between the fear of not being present with the patient and the need to take a break, difficult.

Being isolated at home is one of the disadvantages of home palliative care (63). Many of the informants in this master thesis were both the patients' partner and carer, which made them feel a duality in the caring role. The carers stretch far to fulfil the patients' and the carers' desire to be at home, but the responsibility taking care of a severely ill person affects their own physical or mental health. This can make this role to also be a burden and leading to a barrier caring for the patient at home (63). This was experienced to a greater extent if there were few or no other carers to share the responsibility of taking care of the patient at home. Research has shown that if there is little or no approach or discussion around the carers' own needs and preferences from HCP or the carers' role in providing care is overlooked, caregiving becomes very burdensome and the preference of care at home can change if the carers' or patients' situation makes home care difficult (16, 63, 65, 68, 81).

The carers rights regarding the possibility of facilitation of home care are not only dependable on HCP and HCS but also other authorities like NAV. NAV helps with economic conditions for the patients who receive palliative care and their carers, as the arrangement of attendance allowance (29). Knowing about their own economical rights as carers can contribute to less concern regarding their own workplace. This can also contribute to that the patient can be more at home and that the carers can be more present with the patient. Part of the reason why the informants in this master thesis did not know much about this could be that they did not think

that they had their own rights in this situation as it was the ill who was to be taken care of by the HCS, not those who were “healthy”. Therefore, this has not been a topic one has asked about or mentioned (63). Although, this should be informed about from the HCP, among several other things, regardless of whether the carers ask for it or not. The idea that NAV is to help with financial support in the palliative phase is good and can contribute to a great deal of security in caring for the palliative cancer patient at home. However, many challenges in interaction with this authority were highlighted by the informants in this master thesis. In Lundberg’s Ph.D. thesis (92) where users of NAV were interviewed, the informants experienced resistance in meeting with this authority and met a difficult system where they often did not get what they were entitled to. Many experienced a confusion and disorder in the system and felt that it was a long processing time and many documentation- and information requirements. They had to learn by themselves how NAV worked and what rights they had. They also felt that it was difficult to acquire right and relevant information (92). This is consistent with the findings in this master thesis. It is a burden itself knowing your loved one is dying, and carers need that NAV and the healthcare system will help them through this tough time. Instead, this is experienced as an additional and unnecessary strain and insecurity (66). Studies have shown that financial issues often are a barrier of completion of home palliative care (93, 94) often because the carer has to leave work to manage the care at home (63). By knowing about and receiving financial support, such as attendance allowance, may help to partially overcome this barrier.

None of the informants stated that they had been in contact with a social worker, without this being addressed directly during the interviews. Social support is an important part of palliative care and a social worker should be affiliated with the palliative team and help with social and economic challenges such as various rights and communication with NAV (29). Findings in this master thesis highlight the importance of- and a need for- interdisciplinary cooperation between professionals. In this case, this requires close contact with a social worker with knowledge of palliative care to help carers’ and patients with various economic and social rights and support schemes and a more user- friendly application process within NAV.

The arrangement of attendance allowance was also said to be poorly designed after today’s cancer care and everyday life of carers. The carers cannot know in advance if the patient worsens and needs the carer to be at home, when, or if, other family members can be at home with the patient or if the patient is admitted at the hospital. The carers are therefore in need of a more predictable and easy solution by being able to use the attendance allowance continuously

and at a short notice. Findings in this study support the measures proposed in the Norwegian Official Report (NOU) 2016:17 (31). In the NOU it is proposed that those who have decisions on attendance allowance can also keep/withdraw attendance allowance during a short acute admission to an institution if it is part of the treatment course and further care in the home is planned or the patient is dying (31). This will make the arrangement of attendance allowance more flexible.

Another barrier for home death mentioned was if the planning of this started too late. Sometimes the patient could become acute worse, making the possibility for the planning of home care or transportation from institution to home impossible. This supports the need for early information and planning of time at home and home death if possible. This will depend on cooperation between the specialist- and the municipal HCS and HCP.

4.5 Strengths and Limitations

The qualitative research interview seeks to understand the world from the informant's perspective and aims to produce knowledge within a topic (55). The interview provided room for the informants to deepen their views and provide additional information that they experienced as relevant to their situation. The informants said that they appreciated "being heard", in the sense that there was someone they could physically provide information to and that felt that they contributed to important work. However, many of the questions in the interview guide were formulated to concern things that were positive in the palliative phase. During the interviews, the informants repeatedly drew attention to factors that were perceived as negative and contributed to additional insecurity instead of help in the palliative phase. This may have affected my analysis process. One example is the subcategory "The Norwegian Labour and Welfare Administration" where only negative experiences that contributed to insecurity were highlighted. The opposite of factors that give insecurity are not necessarily factors that provide security and it could therefore be challenging to answer the research questions.

The informants in this study were settled all over the county, from the far north to the south, and lived in various distances from Førde central hospital and therefore had a different infrastructure. The results can therefore be assumed to apply to large parts of the population in the county and other counties that are characterized by similar infrastructure like counties in western Norway and in the north of Norway. Many of the topics brought up during interviews are likely to be the same throughout Norway, like the carers' need for information and HCP

with sufficient competence and knowledge. However, this was a small study with only ten informants from nine families. Even though most of the subjects and challenges that were brought up by the individual informant were similar in many interviews, there were still small differences that could have been emphasized better or other factors that would have emerged if there had been more participants in the study.

All informants in this study were women. Historically, women have had the main role of caregiving, and even today, women have easier to take on care tasks (95, 96). One can therefore imagine that there was greater access to female informants during the study process. It is uncertain how much the results were affected by the informants' gender, but it cannot rule out that it had an impact.

All informants in this study were ethnic Norwegian. The results are therefore dominated by the Norwegian culture and it is not explored whether there are factors that are important for the feeling of security for others with other cultures, backgrounds or religions.

5. Summary and Conclusion

In this master thesis, it is identified factors that have contributed to the carers' feeling of security in care of the advanced cancer patient at home in the county of Sogn og Fjordane. In this context, factors that facilitated home death and factors that were the barriers of home death have also been investigated. The informants have been recruited from different municipalities in Sogn og Fjordane. They have had different experiences in this phase, but many of the factors that contributed to security were similar, regardless of where in the county they lived.

The findings in this master thesis show that support from healthcare professionals and a good organization of the palliative healthcare services play a very important role for giving the carers security in caring for the cancer patient at home in the last phase of life in Sogn og Fjordane. It highlights the importance of having Norwegian-langued healthcare professionals in palliative care in all levels who also have the focus on safeguarding the carers. The contact between healthcare professionals, the patient, and the carers must be based upon understanding and trust. This is achieved when healthcare professionals have knowledge and competence in the field, can provide timely and necessary information, acknowledge and support the carers in their caregiving tasks and when it is clear distribution of roles and responsibility between the healthcare professional and the carer. Continuity in the Home nursing care, close follow-up from the GP and contact with the Palliative care team at Førde central hospital was central elements in the organization of the palliative healthcare offer that contributed to security.

Coordination of care between healthcare providers in hospitals and municipality is necessary for the patient and the carer to feel secure and that the patient can have the opportunity to be cared for, and to die at home if this is the preference. Poor communication, interaction and organization between different healthcare professionals, healthcare services, the Norwegian Labour and Welfare administration and families are barriers that can make it difficult to meet the patient's desire to stay home as long as possible and to die at home. In addition, personal factors like to be present with the patient in the last phase of life, to be several carers and having a driver's license affected the carers' feeling of security. Many of these are factors that healthcare professionals can assess, map and help with in their interaction with the carers.

6. Future Perspectives

Although there is more focus on and knowledge of palliative care in cancer care today, the results from this master thesis have shown that carers in Sogn og Fjordane experience the same challenges as carers in Norway and in other countries do. Even if the involvement of family carers in cancer- and palliative care has been emphasized as important for a long time, there is still a gap between the ideal situation presented in Norwegian official guidelines (13, 29, 31) and everyday practice in the HCS in Sogn og Fjordane. This shows that there is still a need to develop palliative care in Sogn og Fjordane; to ensure a basic knowledge of palliative care among all HCP and HCS and how palliative care has an impact on the closest family, and to ensure a better organization of palliative care throughout the county. This can be done through better education in palliative care among healthcare workers and through the organization of HCSs so that more patients have access to high-quality palliative care. The results from this master thesis can be used to guide this work.

To get a better foundation for improving palliative care in Sogn og Fjordane, there will be a need for more research on the quality of care at the end of life. Other research methods that can investigate this are methods such as questionnaires for carers, mapping of the patients place of care and place of death at the end of life and mapping of the number of home death. There is also a need to investigate this for patient groups other than cancer patients. Even though palliative care mostly has concerned cancer patients, it is equally relevant and important for other patient groups such as patients with heart failure or Amyotrophic Lateral Sclerosis (ALS), among others.

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8. Appendices

Informasjon om masterprosjekt til helsepersonell

Mitt namn er Anne Sæle Barlund

Eg er ein sjukepleiar som til vanleg jobbar ved kreft sengepost på Førde sentralsjukehus, og er no masterstudent i Klinisk Helsevitenskap, studieretning smerte og palliasjon, ved NTNU i Trondheim. Eg held no på med ei masteroppgåve som handlar om å pleie den døyande heime i Sogn og Fjordane, sett frå pårørande sitt perspektiv. Formålet med prosjektet er å undersøkje kva faktorar som gjer at pårørande kjenner seg trygge eller utrygge, kva som bidrog til at dei tok eit val om å pleie pasienten heime, i staden for på institusjon, og i kva grad informasjon og oppfølging helsetenestene har å seie i denne avgjerda.

Eg ønskjer i denne forbindelse å intervjuje etterlatne etter kreftpasientar i Sogn og Fjordane, både dei som har opplevd heimedød og dei som har opplevd død på institusjon. Eg ønskjer å få rekruttert deltakarar over forskjellige delar av fylket på grunn av dei store avstandane som er her som kan gjere at pårørande har forskjellig avstand til sjukehus, andre institusjonar eller helsepersonell. Spesielt ønskjer eg å rekruttere deltakarar som bur i forskjellig avstand til Førde sentralsjukehus, som har den einaste kreftavdelinga og einaste palliativt team i fylket.

Det er ønskjeleg at nokon som allereie er kjende for pårørande, informerer etterlatne om prosjektet. Derfor har eg kontakta deg som er kreftkoordinator, ressursjukepleiar, sjukepleiar i kommunen til pasienten, helsepersonell i palliativt team eller på andre måtar har med kreftpasientar og dykkar pårørande å gjere, for å forspørje om du kan kontakte etterlatne og informere dei kort om prosjektet og spørje dei om det er greitt at eg kontaktar dei etterpå for å gi dei meir informasjon om studien, og eventuelt avtale eit intervju, viss dei ønskjer å delta i studien. Det er utarbeida ein skriftleg mal for kva du kan seie når du kontaktar den etterlatne, samt eit informasjonsskriv til den etterlatne.

Masteroppgåvas tittel: Tryggleik hos pårørande til kreftpasientar i palliativ fase i Sogn og Fjordane – intervju med etterlatne.

Auka kunnskap om dette vil vere av stor betydning når ein planlegger forbetringar av palliativ omsorg i Sogn og Fjordane.

Inklusjonskriteriar:

- Foreldre, barn, eller ektefelle som er etterlatne etter ein kreftpasient (alle \geq 18 år)

- Tidlegare eller noværande kontakt med kreftkoordinator/resurssjukepleiar, sjukepleiar i kommunen eller palliativt team
- Pasientar som ikkje har hatt fastplass/bustaden sin på institusjon
- Moglegheit til å forstå spørsmål og formidle informasjon på norsk eller engelsk.
- Mellom 2 og 12 månadar sidan tap av familiemedlem
- Erfaring frå heimedød eller institusjonsdød, planlagt eller ikkje planlagt.

Det skal vere 8-10 informantar i masterprosjektet, og kvar kommune trenger derfor berre å kontakte 1-2 etterlatne kvar. Det skal intervjuast om lag likt antall etterlatne som har opplevd heimedød som dei som har opplevd institusjonsdød.

Det er ikkje forventa at den etterlatne kjem til Førde sentralsjukehus for intervju. Intervjuet vil bli gjennomført i heimkommunen til den etterlatne i Sogn og Fjordane, eller der det er mest praktisk. Viss informanten må reise, vil vedkommande få refundert kostnadane i ettertid.

Kva ønskjer vi at du bidreg med?

Det vi ønskjer at du som helsepersonell bidreg med, er å kontakte den etterlatne for å gi uforpliktande informasjon om studien, gi informasjonsskriv, få samtykke til at eg kan kontakte vedkommande og eventuelt å hjelpe til med å skaffe eit lokale/rom i kommunen til gjennomføring av intervju.

Eit par dagar etter du har informert den etterlatne om studien, vil eg kontakte vedkommande på telefon (etter eg har fått etterlatne sin kontaktinformasjon frå deg). Dei trenger ikkje ha bestemt seg for å delta i studien før dette. Eg gir meir informasjon om studien, og etterlatne vil få moglegheit til å stille spørsmål. Eg vil ved dette tidspunktet spør om vedkommande ønskjer å delta. Om dei ønskjer dette, avtalar vi eit intervju.

Etterlatne skal skrive under på samtykkeskjema for oppstart av intervju. Dette får dei utdelt av deg når du informerer dei om studien og viss dei aksepterer at eg kontaktar vedkommande. Det presiserast at etterlatne ikkje trenger å skrive under på dette før dei takkar ja til å delta i studien/før eit eventuelt intervju. Det vil bli utført berre eit intervju, og det vil ikkje bli planlagt anna oppfølging enn den kontakten dei har med deg/dykk frå før. Informanten vil kunne kontakte meg i etterkant av intervjuet, viss vedkommande ønskjer dette.

Viss du har ytterlegare spørsmål om masteroppgåva, kan du kontakte meg på e-post:

anne_s_barlund@hotmail.com eller tlf.: 911 57 332

Helsing Anne Sæle Barlund

Appendix 2 When in contact with the bereaved

Når ein kontaktar etterlatne:

Anne Sæle Barlund er sjukepleiar og går no eit masterstudie i smerte og palliasjon (lindrande behandling) ved NTNU i Trondheim. Ho skal no til å skrive ei masteroppgåve som handlar om å pleie den døyande heime i Sogn og Fjordane, sett frå pårørande sitt perspektiv. Formålet med prosjektet er å undersøkje kva faktorar som gjer at pårørande kjenner seg trygge eller utrygge, kva som bidrog til at dei tok eit val om å pleie pasienten heime, i staden for på institusjon, og i kva grad informasjon og oppfølging helsetenestene har å seie i denne avgjerda.

Ho har kontakta meg/oss (kreftkoordinator/resurssjukepleiar/sjukepleiar i kommunen/palliativt team) for hjelp til å rekruttere informantar til studien. Så spørsmålet til deg er om du kunne vore interessert i å få vite litt meir om denne studien. Eg har eit informasjonsskriv, der det står meir detaljert om studien. Viss du er interessert kan eg/vi gi henne kontaktinformasjonen din. Ho vil då kontakte deg om nokre dagar og gi litt meir informasjon om studien, og du har moglegheit til å spørje spørsmål om du har dette. Om du ikkje ønskjer noko meir informasjon om deltaking i ein slik studie er det heilt greit.

Ved interesse om deltaking: i tillegg til informasjonsskrivet får du utdelt eit samtykkeskjema. Dette trenger du ikkje skrive under på før du eventuelt ønskjer å delta i studien. Du får dette utdelt i dag av praktiske grunnar.

Du trenger ikkje bestemme deg i dag om du ønskjer å delta i studien, men får eit par dagar til å tenke litt på dette før ho kontaktar deg. Viss ho får kontakte deg, kan du då svare på om du ønskjer å delta eller ikkje.

Vil du delta i forskingsprosjektet
”Tryggleik hos pårørande til kreftpasientar i palliativ fase i Sogn og Fjordane – intervju med etterlatne ”?

Dette er eit spørsmål til deg om å delta i eit forskingsprosjekt der formålet er å undersøkje kva faktorar som er med på å bidra til tryggleik hjå pårørande som pleier den døyande heime, og kva for erfaringar pårørande har med informasjon og oppfølging frå helsetenesta under omsorg for den døyande. I dette skrivet gjev vi deg informasjon om måla for prosjektet og kva deltaking vil innebære for deg.

Formål

Formålet med prosjektet er å undersøkje kva faktorar som gjer at pårørande kjenner seg trygge eller utrygge, kva som bidrog til at dei tok eit val om å pleie den sjuke heime, i staden for på institusjon, og i kva grad informasjon og oppfølging helsetenestene har å seie i denne avgjerda.

I denne forbindelse vil det bli intervjuet etterlatne etter kreftpasientar i Sogn og Fjordane, både dei som har opplevd heimedød og dei som har opplevd død på institusjon. Det vil bli rekruttert deltakarar over forskjellige delar av fylket på grunn av dei store avstandane som er her som kan gjere at pårørande har forskjellig avstand til sjukehus, andre institusjonar eller helsepersonell. Spesielt er det ønskeleg å rekruttere deltakarar som bur i forskjellig avstand til Førde sentralsjukehus, som har den einaste kreftavdelinga og einaste palliativt team i fylket.

Prosjektet er ei masteroppgåve som blir gjennomført på eitt år, der intervju blir gjennomført i første halvdel (frå august til desember 2018). Det skal vere 8-10 informantar i masterprosjektet. Det skal intervjuast om lag likt antall etterlatne som har opplevd heimedød som dei som har opplevd institusjonsdød.

Kven er ansvarleg for forskingsprosjektet?

Norges teknisk-naturvitskaplege universitet (NTNU) er ansvarleg for prosjektet.

Kvifor får du spørsmål om å delta?

Prosjektet gjeld deg som har mista eit familiemedlem av kreft det siste året og har opplevd å pleie den døyande heime.

Masterstudenten som skal gjennomføre studien har kontakta palliativt team ved Førde Sentralsjukehus og kreftkoordinatorar/ressurssjukepleiarar i Sogn og Fjordane, som igjen har kontakta heimesjukepleie og sjukeheimar i sine kommunar, for å få hjelp til rekruttering til studien. Fordi du har hatt eller har kontakt med nokon av desse, og fordi du oppfyller utvalskriteriane, får du spørsmål om deltaking i studien.

Utvalskriteriane er:

- Foreldre, barn, eller ektefelle som er etterlatne etter ein kreftpasient (alle \geq 18 år)
- Tidlegare eller noverande kontakt med kreftkoordinator/ressurssjukepleiar, sjukepleiar i kommunen eller palliativt team
- Pasientar som ikkje har hatt fastplass/bustaden sin på institusjon
- Moglegheit til å forstå spørsmål og formidle informasjon på norsk eller engelsk.

- Mellom 2 og 12 månadar sidan tap av familiemedlem
- Erfaring frå heimedød eller institusjonsdød, planlagt eller ikkje planlagt.

Kva innebærer det for deg å delta?

Å delta i prosjektet inneber at du blir intervjuet av ein masterstudent som er sjukepleiar. Intervjuet vil bli gjennomført der det er mest praktisk for deg (for eksempel eit rom/lokale i heimkommunen din, på Førde sentralsjukehus, eller andre stader som er mest praktisk for deg). Intervjuet vil vare ca. 1–1.5 time. Det vil bli tatt lydopptak av intervjuet.

Intervjuet vil handle om ulike sider med det å ha opplevd å miste eit familiemedlem med hovudvekt på kjønne erfaringar, ynskjer og behov for informasjon og oppfølging frå helsetenesta under omsorg for den døyande.

Du blir også beden om å fylle ut eit spørjeskjema med opplysningar om deg sjølv og den avdøde: kjønn, fødselsår, utdanningsnivå, busituasjon og kva relasjon du hadde til den avdøde. Etter dette er di deltaking i studien over.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Viss du vel å delta, kan du når som helst trekke samtykke tilbake utan å oppgje noko grunn. Alle opplysningar om deg vil då bli anonymisert. Det vil ikkje ha noko negative konsekvensar for deg viss du ikkje vil delta eller seinare vel å trekke deg.

Ditt personvern – korleis vi oppbevarer og brukar dine opplysningar

Vi vil berre bruke opplysningane om deg til formåla vi har fortalt om i dette skrivet. Vi behandlar opplysningane konfidensielt og i samsvar med personvernregelverket.

- Svare du gir i intervjuet, blir ikkje knytt direkte til ditt namn, fødselsår eller andre direkte gjenkjennande opplysningar. Svare dine blir lagra vha. ein kode som kan koplast til deg gjennom ei namneliste. Namnelista blir oppbevart fråskilt frå sjølve svare dine. Det er berre autorisert personell knytt til prosjektet som har tilgang til namnelista, og som kan finne tilbake til deg.
- Lydopptaka av svare du gir til forskaren, vil bli oppbevart på ei passordbeskytta datamaskin. Opptaket vil bli transkribert på ein måte som gjer at det ikkje er mogleg å identifisere deg.
- Det vil heller ikkje vere mogleg å identifisere deg i resultatane av studien når desse blir publisert.
- Prosjektleder har ansvar for den daglege drifta av forskingsprosjektet, og at opplysningar om deg blir behandla på ein sikker måte.

Kva skjer med opplysningane dine når vi avsluttar forskingsprosjektet?

Prosjektet skal etter planen avsluttast Juni 2019. Informasjon om deg vil bli anonymisert eller sletta seinast 30.06.2019.

Dine rettigheter

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

- innsyn i kva personopplysningar som er registrert om deg,
- å få retta personopplysningar om deg,
- få sletta personopplysningar om deg,
- få utlevert ein kopi av dine personopplysningar (dataportabilitet), og
- å sende klage til personvernombodet eller Datatilsynet om behandlinga av dine personopplysningar.

Kva gjev oss rett til å behandle personopplysningar om deg?

Vi behandlar opplysningar om deg basert på ditt samtykke.

På oppdrag frå NTNU har NSD – Norsk senter for forskingsdata AS vurdert at behandlinga av personopplysningar i dette prosjektet er i samsvar med personvernregelverket.

Kvar kan eg finne ut meir?

Viss du har spørsmål til studien, eller ønsker å nytte deg av dine rettigheter, ta kontakt med:

- NTNU ved Anne Tove Brenne, tlf.: 909 26 353, e-post: anne.tove.brenne@ntnu.no eller masterstudent Anne Sæle Barlund, tlf.: 911 57 332, e-post: anne_s_barlund@hotmail.com.
- Vårt personvernombod: Thomas Helgesen, epost: personvernombud@ntnu.no
- NSD – Norsk senter for forskingsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

Med venleg helsing

Anne Tove Brenne
Prosjektansvarleg

Anne Sæle Barlund
Masterstudent

Samtykkeerklæring

Eg har mottatt og forstått informasjon om prosjektet *Tryggleik hos pårørande til kreftpasientar i palliativ fase i Sogn og Fjordane – intervju med etterlatne* og har fått anledning til å stille spørsmål. Eg samtykker til:

- å delta i intervju
- å delta i spørjeskjema

Eg samtykker til at mine opplysningar blir behandla fram til prosjektet er avslutta, ca. Juni 2019

(Signert av prosjektdeltakar, dato)

Intervjuguide

1. Kan du sei litt om korleis det var for deg å vere pårørande til ein alvorleg sjuk kreftpasient?
 - Kva har vore belastande?
 - Kva har vore givande? Kva har vore viktig for deg?
 - Kva slags følelsar og bekymringar har du hatt?
 - Kva var mest vanskeleg i di rolle som pårørande?
2. Kva fekk deg til å stille opp (som pårørande) i den grad du gjorde?
 - Motivasjon
 - Relasjon
 - Plikt?
3. Kva bidrog til at du følte deg trygg/utrygg i di rolle som pårørande?
 - Enkelt situasjonar i fasar/periodar? Kva skjedde? Kva gjorde du då? Korleis opplevde du det?
4. (Var du/budde du heime med ##? (heile tida, i periodar?))
Var det på nokon tidspunkt krevjande å vere heime med ##?
 - Kva var krevjande?
 - Kva/var det noko som bidrog til å gjere deg trygg i denne situasjonen?
 - Kva/var det noko som bidrog til å gjere deg utrygg i denne situasjonen?
 - Kva kravdest av deg/ kva var din rolle i denne situasjonen?
5. Har det vore annleis å stå i denne rolla (pleie den sjuke heime) enn kva du forventa/såg for deg? /Hadde du nokre forventningar til å stå i denne rolla? (evt. Kva)
6. Var du/dykk nokon gong eller fleire gonger på sjukehus/sjukaheim (i denne lindrande fasen/når det ikkje var tilbudd kurativ behandling)?
 - I kva situasjonar var de på sjukehus? Kva var grunnen til at de reiste på sjukehus?
 - I kva situasjonar var de på sjukaheim? Kva var grunnen til at de reiste på sjukaheim?

7. Korleis var tilgongen på helsetenester/helsehjelp mtp infrastruktur, var dette eit problem? (ferger/båt, lang reiseveg)
8. Hadde de andre kommunale tenester? (Heimesjukepleie, kreftkoordinator)
9. Fekk de hjelp/støtte frå andre enn helsepersonell? (anna familie/vennar/naboar til t.d. avlasting, handling, transport, andre gjeremål)
 - Var hjelp frå andre enn helsepersonell avgjerande for at de vart lenger heime?
 - (Var du/de avhengige av hjelp frå vennar/naboar for at de skulle få vere heime?)
10. Kva hjelp var viktigast når de var heime?
 - Familie, naboar, vennar, helsetilbod, kommune, sjukehus (Var det at de var ein stor/liten familie avgjerande?)
 - Er det lang avstand til anna familie, naboar, vennar, helsetilbod, kommunesenter, sjukehus?
11. Kor mykje hadde de snakka om på førehand om kor ## ønska å vere den siste tida og/eller om at ## skulle døy?
 - Veit du kva ## ville? Kor ville ## vere den siste tida?
 - Var det viktig for deg å oppfylle ## ønske?
 - Føler du at ## ønske førte til at du pressa deg meir til å oppfylle dette enn du ønska sjølv?
 - Skulle du ønske at du og ## hadde snakka tidlegare om den siste tida? (Kor ## ville vere, planlegging, evt dødsstad)
12. Var det viktig å komme heim/få vere heime med den sjuke? Ev. Kva var viktig? (Viktig å komme heim til heimkommunen/heilt heim for å døy, og ikkje på sjukehus?)
13. Då ## døydde heime: Valte de dette/var dette planlagt? Var det ditt, ## eller de saman som valte heimedød? Var dette viktig for dykk? Ev. Kvifor? Kva føler du i ettertid? Er det noko du skulle ønskje blei gjort annleis? Kva positive erfaringar/tankar har du om dette å få vere heime? Kva negativt har du å sei om dette? Var det noko som var vanskeleg med dette valet/i denne situasjonen? Følte du større tryggleik (for deg/for

pasienten) heime enn på institusjon? Ev. Kvifor. Kva føler du hadde vore annleis viss vedkommande var på institusjon?

Då ## døydde på institusjon: Valte de dette/var dette planlagt/føler du at de hadde eit val? Kva var grunnen til valet/ikkje hadde val? Kva var barrierane for å ta vedkommande heim? Ev: Var det ditt, ## eller de saman som valte død på institusjon? Kva føler du i ettertid? Er det noko du skulle ønskje blei gjort annleis? Kva positivt/negativ har du å seie om dette? Var det noko som var vanskeleg med dette valet/ i denne situasjonen? Følte du større tryggleik(for deg, for pasienten) på institusjon enn heime? Ev. Kvifor. Kva føler du hadde vore annleis ved å ha vedkommande heime?

14. Korleis har du opplevd møtet med helsevesenet? - Fortell

- Føler du det har vore god (nok) samhandling/informasjonsutveksling mellom sjukehuset og kommunen i forbindelse med utskriving/innleggelse? Har du følt deg trygg på at kommunen/sjukehuset har vore godt (nok) informert om behov og endringar ved utskriving/innlegging?
- Har de hatt kontakt med fastlegen til pasienten? Har fastlegen deltatt i planlegginga av heimetid/heimedød? Har fastlege vore på heimebesøk? Viss nei: er dette noko du har ynskja?
- Har du hatt kontakt med fastlegen din (i denne fasen, om dette/dine behov)?
- Føler du at du fekk (nok) informasjon om mogleighetene og tilrettelegging for heimetid og ev heimedød? Kva slags informasjon fekk du? Av kven (kommunen, palliativt team, lege eller liknande)?
- Var det noko du grua deg til i denne rolla?
- Fekk du informasjon om kor du kunne henvende deg/kven du kunne kontakte for hjelp/spørsmål?
- Kva informasjon fekk de om dykkar rettigheter som pårørande? for eksempel om pleiepengar? Tok de ut dette?
- Kva tilbod om oppfølging fekk du (som pårørande) frå helsevesenet i den siste fasen? Kva tilbod har du fått i ettertid? Ev: er dette noko du har sakna? Er det noko meir du har sakna?
- Fekk du tilbod om å snakke om bekymringar/erfaringar? (Henvendte helsepersonellet seg til deg, og ikkje berre pasienten, når det gjaldt tankar om plan vidare/forventningar/bekymringar/erfaringar?)

- Føler du at du blei godt nok informert i forkant om kva som venta deg med å ta den sjuke heim?
- Kva er den viktigaste støtta du har fått?
- Er det noko du ynskjer du fekk meir informasjon/støtte/hjelp med?
- Er det noko, evt. Kva, har ikkje vore til hjelp/belastande?
- Har erfaringa di endra synet ditt på norsk helsevesen? – ev. Korleis?

15. Kan du sei 3 stikkord som du trur hadde vore dei viktigaste avgjerande faktorane (for deg) viss du skulle tatt ## heim den siste tida, for at du skulle følt deg trygg/gi deg tryggleik?/Kan du sei 3 stikkord som var dei viktigaste avgjerande faktorane (for deg) for å ta ## heim den siste tida, for at du følte deg trygg/som gav deg tryggleik?

- Hadde du anbefalt ein venn (i same kommune) om å ta den sjuke heim den siste tida, om vedkommande hadde vore i lik situasjon?

16. Er det noko anna du vil tilføye? Noko du syns er viktig å få med som eg ikkje har spurt om?

Appendix 5 Question Form

Spørjeskjema

Fødselsår: _____

Kjønn:

Kvinne Mann

Høgaste fullførte utdanning:

Grunnskule

Vidaregåande

Høgskule/Universitet

Bustad:

Budd saman med den avdøde

Budd i anna bustad enn den avdøde

Forhold til den avdøde:

Ektefelle

Barn

Søster/bror

Forelder

Anna: _____

Avdødes fødselsår: _____

Kjønn på den avdøde:

Kvinne Mann

Avdødes høgaste fullførte utdanning:

Grunnskule

Vidaregåande

Høgskule/universitet

Tidspunkt kreftdiagnose (mnd/år):

_____/_____

Hadde den sjuke subcutan smertepumpe?

Ja Nei

Tidspunkt dødsfall

(mnd/år): _____/_____

Dødsstad:

Heime

Sjukehus

Sjukeheim

Anna: _____

Tid sidan dødsfall (mnd eller veker):



NTNU
Att: Anne-Tove Brenne
anne.tove.brenne@ntnu.no
Anne Sæle Barlund
annesba@stud.ntnu.no

Vår dato: 03.09.2018

Vår ref: 61366 AMS/LR

Deres dato:

Deres ref:

VURDERING AV BEHANDLING AV SÆRSKILTE KATEGORIER PERSONOPPLYSNINGER I PROSJEKTET : TRYGGLEIK HOS PÅRØRANDE TIL KREFTPASIENTAR I PALIATIV FASE I SOGN OG FJORDANE- INTERVJU MED ETTERLATNE

NSD - Norsk senter for forskningsdata AS viser til meldeskjema innsendt 29.06.2018. Meldingen gjelder behandling av personopplysninger til forskningsformål.

Etter avtale med den behandlingsansvarlige, NTNU, har NSD foretatt en vurdering av om den planlagte behandlingen er i samsvar med personvernlovgivningen.

Resultat av NSDs vurdering:

NSD vurderer at det vil bli behandlet særskilte kategorier personopplysninger frem til 30.06.2019.

NSDs vurdering er at behandlingen vil være i samsvar med personvernlovgivningen, og at lovlig grunnlag for behandlingen er samtykke.

Vår vurdering forutsetter at prosjektansvarlig behandler personopplysninger i tråd med:

- opplysninger gitt i meldeskjema og øvrig dokumentasjon
- dialog med NSD, og vår vurdering (se under)
- NTNU sine retningslinjer for datasikkerhet, herunder regler om hvilke tekniske hjelpemidler det er tillatt å bruke

Nærmere begrunnelse for NSDs vurdering:

1. Beskrivelse av den planlagte behandlingen av personopplysninger:

Formålet er «å undersøke kva faktorar som er med på å bidra til tryggleik hos pårørande som pleier kreftpasientar heime mot slutten av livet i Sogn og Fjordane, eit fylke med spreidd busetnad, fjordar og fjell og ofte lang avstand til næraste helseinstitusjon og sjukehus.»

Datamaterialet vil innhentes gjennom intervjuer med pårørende til avdøde kreftpasienter. Opplysninger om pasienten registreres også på spørreskjema på papir.

NSD mottok reviderte informasjonsskriv 21.08.2018. Disse er godt utformet, men angir at prosjektslutt er 30.06.2019. I meldeskjemaet var prosjektslutt angitt til 2022. I tråd med informasjonsskrivet er prosjektslutt justert til 30.06.2019 i meldeskjemaet.

Studenten opplyser at helsepersonell ber om samtykke til å videreformidle kontaktinformasjon til pårørende som vil delta i prosjektet. NSD forutsetter da at helsepersonell har informert om alle relevante sider ved prosjektet før pårørende samtykker. I tillegg må studenten fornye samtykket før oppstart av intervju og datainnsamling for å sikre at all informasjon er gitt.

2. Personvernprinsipper

NSDs vurdering er at behandlingen følger personvernprinsippene, ved at personopplysninger;

- skal behandles på en lovlig, rettferdig og åpen måte med hensyn til den registrerte
- skal samles inn for spesifikke, uttrykkelig angitte og berettigede formål og der personopplysningene ikke viderebehandles på en måte som er uforenelig med
- vil være adekvate, relevante og begrenset til det som er nødvendig for formålet de behandles for
- skal lagres slik måte at det ikke er mulig å identifisere de registrerte lengre enn det som er nødvendig for formålet

3. Lovlig grunnlag for å behandle særskilte kategorier

1) Særskilte kategorier - Samtykke ((art. 6.1. a), art. 9.2 a))

Det fremgår av meldeskjema vi har fått tilsendt at det vil bli innhentet samtykke fra de registrerte.

NSD vurderer at den planlagte behandlingen av personopplysninger er lovlig fordi:

- det skal innhentes uttrykkelig samtykke fra de registrerte og
- forsker har oppfylt den særskilte rådføringsplikten

4. De registrertes rettigheter

NSD vurderer at den registrerte har krav på å benytte seg av følgende rettigheter: informasjon, innsyn, retting og sletting av personopplysninger, dataportabilitet, protest.

NSD finner at informasjonsskrivet vil gi de registrerte god informasjon om hva behandlingen innebærer og om hvilke rettigheter de har.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har NTNU plikt til å svare innen en måned. Vi forutsetter at prosjektansvarlig informerer institusjonen så fort som mulig og at Nord universitet har rutiner for hvordan henvendelser fra registrerte skal følges opp.

5. Informasjonssikkerhet

NSD forutsetter at personopplysningene behandles i tråd med personvernforordningens krav og institusjonens retningslinjer for informasjonssikkerhet.

6. Varighet

Ifølge meldeskjema skal personopplysninger behandles frem til 30.06.2019. Personopplysninger som kan knyttes til en enkeltperson skal da slettes/anonymiseres.

NTNU må kunne dokumentere at datamaterialet er anonymisert.

Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan bli identifisert. Det gjøres ved å

- Slette navn, fødselsnummer/andre ID-nummer, adresse, telefonnummer, epostadresse, IP-adresse og andre nettidifikatorer
- Slette eller grovkategorisere bakgrunnsopplysninger
- Slette eller sladde bilder/videopptak og lydopptak

NTNU må kunne dokumentere at datamaterialet er anonymisert.

Meld fra om endringer

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

Informasjon om behandlingen publiseres på Min side, Meldingsarkivet og nettsider

Alle relevante saksopplysninger og dokumenter er tilgjengelig:

- via Min side for forskere, veiledere og studenter
- via Meldingsarkivet for ansatte med internkontrolloppgaver ved NTNU.

NSD tar kontakt om status for behandling av personopplysninger

Etter avtale med NTNU vil NSD følge opp behandlingen av personopplysninger underveis, og ved planlagt avslutning.

Vi sender da en skriftlig henvendelse til prosjektansvarlig og ber om skriftlig svar på status for behandling av personopplysninger.

Se våre nettsider eller ta kontakt ved spørsmål. Vi ønsker lykke til med prosjektet.

Med vennlig hilsen



Marianne Høgetveit Myhren
seksjonsleder



Anne-Mette Somby
spesialrådgiver

