

Family challenges in the palliative phase of an elderly family member suffering from cancer.

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ABSTRACT IN ENGLISH

Background

An ageing population will lead to an increasing prevalence of cancer and thus an increase in elderly cancer patients in the palliative phase in the years to come. With health policy goals for patients to spend more time at home, it is most often the closest family members who become responsible for attending to the patient for the bigger part of the day. The patient's and family members' experience of the situation is influenced by factors including the condition of the patient, whether family members are in a position to provide care, and how well the family is able to help and support each other. The relationships provide mutual help and support, and cancer disease in the palliative phase therefore affects not only the patient and the family members as individuals, but also the family relationships and the family as a whole. Little research has specifically explored the experiences and needs of elderly cancer patients in the palliative phase and / or their immediate family members. Furthermore, few studies have investigated how cancer in the palliative phase affects family relationships and

the family as a whole, and few studies have collected data through family group interviews. When the patient is elderly, the entire immediate family becomes involved in the caregiving. Nevertheless, few studies, in the case of cancer in the palliative phase, have assessed and compared caregiver reactions and access to social support among family members with different relationships with the patient. It is therefore important to acquire more knowledge about families' challenges in the case of palliative cancer.

Aim

The overall aim of this study is to develop knowledge about what is important and difficult in families when an elderly adult family member has cancer in the palliative phase. The thesis is based on three studies which explore: 1) what elderly cancer patients and their family members experience as important and difficult in close family relationships during the palliative phase, and how they interact and communicate about these challenges, 2) an assessment and comparison of caregiver reactions and social provisions among different family caregiver groups caring for home-dwelling elderly adult cancer patients during the palliative phase, and 3) what elderly home-dwelling cancer patients in the palliative phase and their close family members, as individuals and as a family, experience as important and difficult when interacting with health care service.

Methods

In order to answer the research questions, a design has been chosen that combines qualitative and quantitative methods, but not in the same substudies. Nurses and doctors employed in the home nursing service and hospitals in three counties in Western Norway invited families consisting of one patient in the palliative phase ≥ 65 years and up to 4 family members to participate. Twenty-six ethnic Nordic families participated, a total of 86 people. The average age of the patients was 79 years. Data for all three substudies were collected simultaneously.

Substudies 1 and 3 have a qualitative design. Data were collected through family group interviews, which provided the opportunity to collect data on several levels (e.g. individual, dyad, family unit), and with different perspectives (e.g. experiences and needs, interactions and processes). Inductive content analysis was used to analyse data. Substudy 2 has a quantitative design, in which the patients' family members completed two questionnaires immediately after the end of the interview. The Norwegian versions of the Caregiver Reaction Assessment (CRA) and Social Provisions Scale (SPS) form the basis of data for this substudy. The data were analysed with descriptive statistics.

Results

The main theme of substudy 1 is 'a valuable but demanding time'. The most important thing for the families was to ensure a positive final time together. At the same time, there were challenges relating to the different needs of patients and family members, which were sometimes difficult to understand and accommodate. Since patients and family members hid and concealed thoughts, feelings, and needs from each other, the opportunities for discussing the various needs were compromised, which could result in tensions and conflicts in family relationships. Substudy 2 shows that family members with different relationships to the patient can each experience care responsibilities and access to social support differently. Caregiving responsibilities were most challenging for patients' spouses and for children/children-in-law of widowed patients. Spouses reported a significantly more disrupted schedule, while children/children-in-law, especially those who cared for widowed patients, experienced the greatest lack of family support. Children/children-in-law to widowed patients also experienced more often than children/children-in-law to married patients that their own health had deteriorated. Regarding social support, the results show that children/children-in-law to widowed patients had less attachment support than children/children-in-laws to married patients. The main finding in the third substudy is that the health care service was

inadequately structured around the families' needs. The hospitals' cancer follow-up care, both in terms of tumour-directed palliative treatment and the journeys to hospitals, was very exhausting for the patients. The patients were unable or unwilling to maintain contact with the health care service and had delegated this responsibility to their family members. However, it was difficult for many family members to become involved in the health care service's follow-up care of the patient. The families also experienced little continuity among the staff under whose care they were, which led to the health care being fragmented and the families going out of their way to avoid using the health care service.

Conclusions

Cancer in the palliative phase of an elderly home-dwelling family member, including experiences with the health care service, challenged family relationships and the family as a whole, which could reduce the opportunities for them to spend a positive final time together. Families may therefore need help and support to deal with relationship challenges resulting from the situation caused by the illness. In order for the health care service to adapt its work around the family's need for help and support, the health care service must consider the family as a unit and develop systems to facilitate family involvement in the health care service's follow-up care of the patient. Such help and support could help the patient to be at home as much as possible, enable family members to cope with the caregiving responsibilities at home without becoming exhausted or ill, and allow families to have a positive time together at home.

ABSTRACT IN NORWEGIAN

Bakgrunn

En aldrende befolkning vil medføre økende prevalens av kreft og dermed flere eldre kreftpasienter i palliativ fase i årene som kommer. Med helsepolitiske målsetninger om at pasienter skal tilbringe mest mulig tid hjemme, blir det oftest nærmeste familiemedlemmer som får ansvaret for å følge opp pasienten de fleste timer i døgnet. Hvordan pasienten og familiemedlemmene opplever situasjonen påvirkes blant annet av pasientens tilstand, familiemedlemmenes omsorgssituasjon og hvor godt familien klarer å hjelpe og støtte hverandre. Hjelpen og støtten utveksles i relasjonene, og kreftsykdom i palliativ fase påvirker derfor ikke bare pasienten og familiemedlemmene som enkeltindivider, men også familierelasjonene og familien som helhet. Lite forskning har spesifikt utforsket erfaringer og behov hos eldre kreftpasienter i palliativ fase og/eller deres nærmeste familiemedlemmer. Videre har få studier utforsket hvordan kreftsykdom i palliativ fase påvirker familierelasjonene og familien som helhet, og få studier har samlet data ved familiegruppeintervju. Når pasienten er eldre, blir gjerne hele nærmeste familie involvert i omsorgsansvaret. Likevel har få studier, ved kreftsykdom i palliativ fase, kartlagt og sammenlignet reaksjoner på omsorgsansvar og tilgang på sosial støtte hos familiemedlemmer med ulik relasjonell tilknytning til pasienten. Det er derfor viktig å fremskaffe mer kunnskap om familiers utfordringer ved kreftsykdom i palliativ fase.

Hensikt

Det overordnede formålet med denne studien er å utvikle kunnskap om hva som er viktig og vanskelig i familier som følge av kreftsykdom i palliativ fase hos et eldre familiemedlem. Avhandlingen er basert på tre delstudier med følgende hensikt: 1) å undersøke hva eldre kreftpasienter og deres familiemedlemmer opplever som viktig og vanskelig i nære

familierelasjoner i palliativ fase, og hvordan de samhandler og kommuniserer om det vanskelige, 2) å kartlegge og sammenligne reaksjoner på pleie- og omsorgsansvar og sosial støtte blant ulike grupper familieomsorgspersoner til hjemmeboende eldre kreftpasienter i palliativ fase, og 3) å undersøke hva eldre hjemmeboende kreftpasienter i palliativ fase og deres nærmeste familiemedlemmer, som individ og som familie, opplever er viktig og vanskelig i møte med helsetjenesten.

Metode

For å besvare forskningsspørsmålene er det valgt et design som kombinerer kvalitativ og kvantitativ metode, men ikke i samme delstudier. Sykepleiere ansatt i hjemmesykepleien og sykehus i tre fylker i Vest-Norge inviterte familier bestående av en pasient i palliativ fase ≥ 65 år og inntil 4 familiemedlemmer til å delta. Tjuseks etnisk nordiske familier deltok, totalt 86 personer. Pasientenes gjennomsnittsalder er 79 år. Data til alle tre delstudiene ble samlet inn samtidig. Delstudie 1 og 3 har et kvalitativt design. Data ble samlet inn ved familiegruppeintervju, som ga anledning til å samle data på flere nivå (eks. individ, dyade, familieenhet), og med ulike perspektiver (eks. erfaringer og behov, interaksjoner og prosesser). Induktiv innholdsanalyse ble brukt til å analysere data. Delstudie 2 har et kvantitativt design, hvor pasientenes familiemedlemmer fylte ut to spørreskjemaer umiddelbart etter avsluttet intervju. De norske versjonene av The Caregiver Reaction Assessment (CRA) og Social Provisions scale (SPS) er datagrunnlaget for denne delstudien. Dataene ble analysert med deskriptiv statistikk.

Funn

Hovedtema i delstudie 1 er «en verdifull, men vanskelig tid». Det viktigste for familiene var å sikre en mest mulig positiv sistetid sammen. Samtidig var det tilstede utfordringer relatert til pasienter og familiemedlemmers forskjellige behov, som noen ganger var vanskelig å forstå

og imøtekomme. Siden pasienter og familiemedlemmer skjulte tanker, følelser og behov for hverandre, ble mulighetene for å diskutere de ulike behovene svekket, noe som kunne resultere i spenninger og konflikter i familierelasjonene. Delstudie 2 viser at familiemedlemmer med ulik relasjonell tilknytning til pasienten både kan oppleve omsorgsansvaret og tilgangen på sosial støtte ulikt. Omsorgsansvaret var mest utfordrende for pasientenes ektefeller, og for barn/svigerbarn med omsorg for pasienter uten ektefelle. Flest ektefeller rapporterte at omsorgsansvaret forstyrret dagliglivets rutiner, mens barn og svigerbarn, spesielt de med omsorg for pasienter uten ektefelle, savnet mest familiestøtte. Barn/svigerbarn til pasienter uten ektefelle opplevde også oftere enn barn/svigerbarn til pasienter med ektefelle at egen helse var blitt forverret. Vedrørende sosial støtte viser resultatene at barn/svigerbarn til pasienter uten ektefelle hadde mindre tilknytningsstøtte enn barn/svigerbarn til pasienter med ektefelle. Hovedfunn i tredje delstudie er at helsetjenesten ikke var tilpasset familienes behov for helsehjelp. Sykehusenes kreftoppfølging, både tumorrettet palliativ behandling og reisene til sykehus, var svært anstrengende for pasientene. Pasientene klarte ikke, eller ønsket ikke selv å holde kontakten med helsetjenesten, og hadde overlatt dette ansvaret til sine nærmeste familiemedlemmer. Imidlertid var det vanskelig for mange av familiemedlemmene å bli involvert i helsetjenestens oppfølging av pasienten. Familiene opplevde også liten kontinuitet blant personalet som fulgte dem opp, noe som førte til at helsehjelpen opplevdes fragmentert, og at familiene strakk seg langt for å slippe å bruke helsetjenesten.

Konklusjon

Kreftsykdom i palliativ fase hos et eldre hjemmeboende familiemedlem, inklusiv møtene med helsetjenesten, utfordret familierelasjonene og familien som helhet, noe som kunne vanskeliggjøre mulighetene for en positiv siste tid sammen. Familier kan derfor ha behov for hjelp og støtte til å håndtere relasjonelle utfordringer som følge av kreftsykdommens

utfordringer. For at helsetjenestetiltak skal være tilpasset familienes behov for hjelp og støtte, må helsetjenesten møte familien som system, og utvikle systemer for familieinvolvering i helsetjenestens oppfølging av pasienten. Slik hjelp og støtte vil kunne bidra til at pasienten kan være mest mulig hjemme, at familiemedlemmene kan klare omsorgsansvaret hjemme uten å bli utslitt eller syke og til at familiene kan ha en positiv sistetid sammen hjemme.

LIST OF PAPERS

Paper 1: Fjose, M., Eilertsen, G., Kirkevold, M., Grov, EK. (2016) *A valuable but demanding time. Family life during advanced cancer in an elderly family member*. *Advances in Nursing Science*, Vol 39 Issue 4, pp 358-373.

Paper 2: Fjose, M., Eilertsen, G., Kirkevold, M., Grov, EK. (submitted) *Caregiver reactions and social provisions among family members caring for home-dwelling patients with cancer in the palliative phase: A cross-sectional study*.

Paper 3: Fjose, M., Eilertsen, G., Kirkevold, M., Grov, EK. (2018) *'Non-palliative care' – A qualitative study of older cancer patients' and their family members' experiences with the health care system*. *BMC Health Services Research* 18:745

ABBREVIATIONS

CRA	The Caregiver Reaction Assessment
GP	General practitioner
SPS	The Social Provisions Scale
WHO	World Health Organisation

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1 INTRODUCTION

This study was performed in order to obtain knowledge about what is important and difficult in families as a consequence of cancer in the palliative phase in an elderly home-dwelling family member. Over 33,500 people were diagnosed with cancer in Norway in 2017, and 10,994 died of the disease in 2016 (Cancer Registry of Norway, 2018). Cancer incidence increases with age, and three quarters of all those suffering from cancer in the palliative phase are over 65 years old (Cancer Registry of Norway, 2018; Cancer Research UK, 2014). An ageing population will therefore result in a greater number of elderly people with cancer in the palliative phase in the years to come. (Cancer Registry of Norway, 2018; Lindskog, Tavelin, & Lundstrom, 2015; Sommerbakk, Haugen, Tjora, Kaasa, & Hjermstad, 2016). Research focusing specifically on elderly cancer patients is limited (Brighi, Balducci, & Biasco, 2014; Haug, Danbolt, Kvigne, & Demarinis, 2015; Thompson, 2010). The target group in this study is therefore families with elderly cancer patients in the palliative phase.

The family is an important resource, both for the patient, family members and the health care service in cases of cancer in the palliative phase (Ministry of Health and Care Services, 2013; Sandsdalen, Hov, Høye, Rystedt, & Wilde-Larsson, 2015; Sparla et al., 2016; Ward-Griffin, McWilliam, & Oudshoorn, 2012). However, cancer in the palliative phase challenges the family (Mehta, Cohen, & Chan, 2009; Molassiotis, Wilson, Blair, Howe, & Cavet, 2011; Waldrop, Milch, & Skretny, 2005); for example, it can be difficult for patients and family members to help and support each other (Stajduhar, Martin, Barwich, & Fyles, 2008; Ward-Griffin et al., 2012). Specific knowledge about what families perceive as difficult and important in cases of cancer in the palliative phase in an elderly home-dwelling family member could help to provide insight into what the family's needs are, and what help and support the family needs in order to cope with the challenges posed by advanced cancer in the family.

We may apply theories to illustrate what families are and how they are. A central theory of understanding about what happens in families in cases of illness is the systems theory (Wright & Leahey, 2013). Few studies in the context of cancer in the palliative phase have had a family systems perspective (Mehta et al., 2009; Møllerberg, Sandgren, Swahnberg, & Benzein, 2017), which is why this perspective was chosen for this study. The family systems theory draws attention to relationships, interactions and reciprocity in families, between families and health and illness, and between families and other systems such as the health care system (Wright & Leahey, 2013). The reciprocity in the family system means that individual members' reactions and needs affect all other members of the family and the family as a whole. The focus in this study therefore became to explore what is important and difficult in close family relationships as a result of cancer in the palliative phase in an elderly home-dwelling family member, including the results of experiences with the health care service. A further focus became to identify and compare caregiver reactions and access to social support among family members with different relational connections to the patient.

2 THE FAMILY IN CASES OF CANCER IN THE PALLIATIVE PHASE

2.1 The concept of family

There is no general definition of the concept of family (Kaakinen & Hanson, 2015; Wright & Leahey, 2013). Traditionally, the core family consisting of a mother, father and children has been a widely used definition. This definition limits the family to people connected by blood or marriage (Wright & Leahey, 2013). The diversity of potential family compositions in today's society, as a consequence of divorce, adoption and same-sex marriage etc., makes it necessary to apply a definition which transcends traditional definitions (Kaakinen & Hanson, 2015; Wright & Leahey, 2013). Wright and Bell (2009) have defined the family as: 'A family

is a group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another's lives' (p. 46). For this study we have chosen a definition which allows families to define themselves: 'The family is who they say they are' (Wright & Leahey, 2013).

2.2 Family caregiving before and now

Historically, the family has always played an important role in cases of illness in its members (Hoffmann & Mitchell, 1998; Kaakinen & Hanson, 2015; Wright & Leahey, 2013). However, it is claimed that the growth of the welfare state in the 20th century, with institutionalisation of care, has robbed the family of the responsibility of care for sick family members (Kaakinen & Hanson, 2015; Lingsom, 1997; Wright & Leahey, 2013). Research into the development of family caregiving in the period between 1960 and 1990 also shows that family caregiving in Norway has remained stable, probably due to a health policy focus on developing the home care service (home nursing and home health) (Lingsom, 1997). The development of medicine in the 20th century, with better options for treatment and relief, has also acted as a supplement to family caregiving (Lingsom, 1997).

With an ageing population and limited financial resources, modern society is once again faced with a need to reorganise health care services. The Coordination Reform, which was introduced in Norway in 2012, has the objective of getting municipal health care services to take over more of the responsibility for the treatment and care of patients who can live at home. Patients are therefore discharged from hospital and sent home more quickly now than only a few years ago (Hermansen & Grødem, 2015; Sommerbakk et al., 2016). This results in increased responsibility and pressure on the family to take on extensive nursing and care tasks (Benzein, Hagberg, & Saveman, 2012; Kaakinen & Hanson, 2015; Northouse, 2012; Wright & Leahey, 2013). Yet living at home, and if possible dying at home, is the wish of many patients and family members (Collier, Phillips, & Iedema, 2015; Gomes, Calanzani, Gysels,

Hall, & Higginson, 2013; Milligan et al., 2016), even when the patient is elderly (Esbensen, Swane, Hallberg, & Thome, 2008), and when the elderly person lives alone (Hanratty et al., 2013).

2.2.1 Norwegian health care policy objectives for family caregiving

In Norway today, it is stipulated that family caregiving should form at least 50% of the total caregiving, and Official Norwegian Reports (NOUs) have established that in order to handle the challenges resulting from an ageing population, family caregiving must also be kept at the current level in the future (Daatland, Veenstra, & Lima, 2009; Lingsom, 1997; Ministry of Health and Care Services, 2013; NOU 2011:17, 2011). The family does not have a legal obligation to take on caregiving responsibilities for family members over the age of 18 (Ministry of Health and Care Services, 2013; Norwegian Directorate of Health, 2017). The reports, which use the term next of kin, therefore claim that the next of kin's role in caring for sick family members must be made visible and acknowledged, and that the health care service must develop better coordination with and support for next of kin (Ministry of Health and Care Services, 2013, 2015; NOU 2011:17, 2011; NOU 2017:16, 2017). To improve the health care service's involvement and support for next of kin, the Norwegian Directorate of Health published a guide for next of kin in January 2017 (Norwegian Directorate of Health, 2017). This states that municipalities and health trusts must provide tailored support, training, guidance and the option of a contact person. Municipalities must also offer respite care.

An appraisal of the public studies and the guide for next of kin is that their main focus is on the individual needs of patients and their family members. There is little focus on how to help and support the family unit to deal with the situation caused by the illness. Patients live with their illness within their family (Kaakinen & Hanson, 2015), and decisions on applying for and making use of measures provided by the health care service are often made jointly by the family as a whole (Kaakinen & Hanson, 2015; Parahoo, 2008). Report No 26 to the Storting

(2014–2015) ‘The primary health and care services of tomorrow’ points out that more knowledge is needed about the status and development of family caregiving. Knowledge about what is important and difficult in families as a consequence of cancer in the palliative phase can contribute to insight into what the family’s needs are, and thereby contribute to increased knowledge about how the health care service can help and support the family.

2.3 Family caregiving in cases of cancer in the palliative phase

2.3.1 The family relationships are important – but become challenged

Patients and family members have both reported that close relationships are important in cases of cancer in the palliative phase (Drabe, Wittmann, Zwahlen, Büchi, & Jenewein, 2013; Gjertsen, 2009; McKechnie, MacLeod, & Keeling, 2007). The quality of family relationships has been found to be significant in how well families manage to adapt to situations involving nursing and death in the home (Collier et al., 2015; Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004; Milligan et al., 2016). Patients and family members most often find that their relationships become closer, but some also report that the quality of the relationship is unchanged, or becomes worse (Drabe et al., 2013; Northfield & Nebauer, 2010).

Cancer can evoke strong emotional reactions both in patients and family members (Peter L. Hudson, Thomas, Trauer, Remedios, & Clarke, 2011; Northouse, 2012; Zwahlen, Hagenbuch, Jenewein, Carley, & Buchi, 2011). Although a review reports that elderly cancer patients admit to less emotional stress than younger patients (Thompson, 2010), emotional stress has also been reported in elderly cancer patients (Devik, Hellzen, & Enmarker, 2017; Esbensen et al., 2008; Jo, Brazil, Lohfeld, & Willison, 2007). Patients and family members are reciprocally affected by each other’s emotional stress (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Lo et al., 2013; Mystakidou et al., 2013). Emotional stress can therefore disrupt family relationships (Badr & Taylor, 2006; Gardner, 2008). As the cancer develops, the patient becomes more and more reliant on help; elderly patients often more so

and at an earlier stage than younger patients (Bellury et al., 2011; Grov, Fosså, & Dahl, 2010a). This means that the family's daily routines must be restructured, tasks and responsibilities left to close family members, and the load on the family members increases (B. Given, Given, & Sherwood, 2012; Haug et al., 2015; Zwahlen et al., 2011).

2.3.2 The responsibility for caregiving challenges the family

In cases of cancer in the palliative phase, it is most often the patient's spouse or daughters who have the responsibility for caregiving at home, but sons, other family members and friends also contribute (Funk et al., 2010; T. Morgan, Williams, Trussardi, & Gott, 2016; Sutherland, Ward-Griffin, McWilliam, & Stajduhar, 2017). When the patient is elderly, the availability of family members can be a challenge (Higginson, Sarmiento, Calanzani, Benalia, & Gomes, 2013; Thompson, 2010). The spouse may be frail, ill or deceased, and the responsibility for caregiving is left to adult children and if necessary other family members (Balducci & Dolan, 2016; Bastawrous, 2012; Hoffman, 2008). Adult children often have other responsibilities (such as work and caring for their own children), and the responsibility for caregiving can therefore be shared by several family members (Hoffman, 2008; Tolkacheva, Van Groenou, & Van Tilburg, 2011).

The responsibility for caring for a cancer patient in the palliative phase has been shown to affect family members physically, mentally, socially and existentially, and both positively and negatively (B. Given et al., 2012; Northouse, 2012). Positive aspects can be maturation and growth (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003; Grande et al., 2009; Stajduhar, 2013); negative aspects can be stress and exhaustion (Grande et al., 2009; Northouse, 2012; Stajduhar, 2013). Access to help and support from family and friends can reduce the negative aspects of family members' caregiving responsibilities (Gaugler et al., 2005; Wright & Leahey, 2013). Help and support from family and friends can also be difficult and contradictory. Family caregivers have reported that family and friends only have a focus on

the patient (Stajduhar et al., 2008; Ward-Griffin et al., 2012), that the help they offer is not always helpful (Foxwell & Scott, 2011; Sjövall, Gunnars, Olsson, & Thomé, 2011), and that it can be difficult to ask for and receive help and support (Andershed & Ternstedt, 2006; Wittenberg-Lyles, Washington, Demiris, Oliver, & Shaunfield, 2013). How well patients and family members manage to help and support each other also depends on the quality of the relationships (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Wright & Leahey, 2013; Zaider & Kissane, 2009).

Knowledge about family members' caregiver reactions is important in order to tailor help and support to counteract stress, exhaustion and poor health (Bastawrous, 2012; Northouse, 2012; Stajduhar, 2013). Help and support are exchanged in the relationships, which means that caregiver reactions not only affects the family caregivers individually, but also the patient and other close family members, the family relationships and the family unit (Balducci & Dolan, 2016; Northouse, 2012; Zaider & Kissane, 2009). Help and support which reduce family members' caregiver reactions can therefore also have a positive effect on other members of the family and the family unit.

2.4 Cancer in the palliative phase and the health care service

2.4.1 Cancer in the palliative phase in the older years

Ageing tends to bring a number of losses: biological, mental and social (Haug et al., 2015; Thompson, 2010). Comorbidity is common (Bellury et al., 2011; Marengoni et al., 2011; Wedding & Stauder, 2014), and can result in frailty, organ failure, polypharmacy and cognitive failure (Dahl & Grov, 2014). In elderly cancer patients, comorbidity can result in a more extensive symptom burden (Bellury et al., 2011; Van Lancker, Beeckman, Van Den Noortgate, Verhaeghe, & Van Hecke, 2017), more difficult cancer treatment (Brighi et al., 2014; Janssen-Heijnen et al., 2014; Wedding & Stauder, 2014), including difficulties getting to hospital for follow-up care (Balducci & Dolan, 2016). Because of visual and hearing

impairment and cognitive failure, ageing can also make communication with the health care service more difficult (Balducci & Dolan, 2016; Sparks & Nussbaum, 2008; Thompson, 2010). This means that elderly cancer patients in the palliative phase can need more help and at an earlier stage from the family and the health care service than younger patients (Bellury et al., 2011; B. Given et al., 2012; Grov, Fosså, & Dahl, 2010b).

2.4.2 How the health care service is structured in Norway

The basic structure of the health care service in Norway is essentially made up of the municipal health care service and specialist health care service. The municipal health care service mainly includes general practitioners (GPs), home-based services such as the home nursing service and home health, nursing homes and emergency medical centres. The GP is the doctor responsible for the patient, and has the overall, coordinating responsibility for care and treatment (Romøren, Torjesen, & Landmark, 2011). The specialist health care service primarily includes local, county and regional hospitals (Romøren et al., 2011; Sommerbakk et al., 2016). In addition, as a consequence of the Coordination Reform (Ministry of Health and Care Services, 2009), district medical centres have been established where municipal health care service and specialist health care service are co-located, in order to be able to provide assessments and treatment as close to the patient's home as possible.

2.4.2.1 *How cancer follow-up care is structured*

Patients with cancer in the palliative phase can have multiple and complex symptoms (Shamieh et al., 2017). This means that keeping the disease in check and alleviating symptoms can be complex and interdisciplinary, and extend well into the palliative phase (Aabom & Pfeiffer, 2009; G. Clarke, Johnston, Corrie, Kuhn, & Barclay, 2015; Walsh et al., 2010). It is most often oncologists at the hospitals' outpatient clinics who tend to handle cancer follow-up care (B. Given et al., 2012; Walsh et al., 2010). As the disease progresses, patients will also need nursing and care from the municipal health care service. Consequently,

patients and their families often receive follow-up care from different levels of the health care service at the same time. Elderly patients often have several symptoms simultaneously, which means that coordination with the health care service becomes complex and challenging.

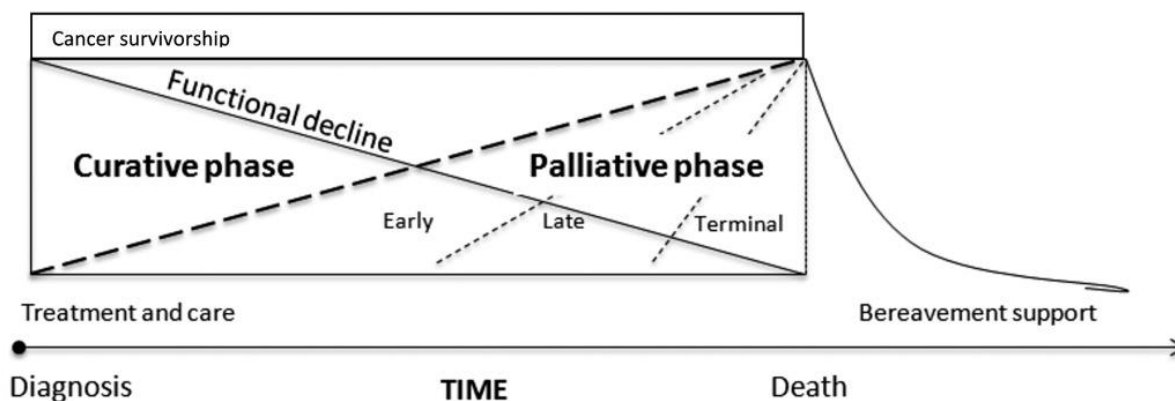
2.4.2.2 Palliative care in Norway

The World Health Organisation's (WHO) definition of palliative care is cited in a number of Norwegian public documents as the target for palliative care in Norway (Norwegian Directorate of Health, 2015; NOU 2017:16, 2017):

'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' (World Health Organization, 2017).

This definition emphasises that the focus of palliative care is both the patient and their family. The palliative phase typically has a number of transition phases, and Grov (2014) has developed a model which provides a visual picture of the phases of the cancer trajectory, with a line which indicates the patient's gradual reduction in physical capacity (Figure 1). The dotted lines represent transitions between phases, which are difficult to define precisely.

Figure 1.



The WHO's definition of palliative care does not have a time estimate, and the palliative phase can be as short as a few days, or last for months or years. In the early palliative phase, the patient often has no symptoms and is in good physical condition. The late palliative phase typically has more symptoms which can have an effect on the patient's functional level (Gro, 2014).

Palliative health care service in Norway are structured in line with recommendations from the European Association for Palliative Care (European Association for Palliative care, 2010; Norwegian Directorate of Health, 2015; Sommerbakk et al., 2016), and on a global basis, Norway is ranked as a country with a well-developed palliative health care service (Lynch, Connor, & Clark, 2013). All departments in the municipal and specialist health care service which treat seriously ill and dying patients must be able to provide fundamental palliative care. Oncology centres at hospitals must also be able to provide specialised palliative care to patients with a more complicated set of symptoms. Oncology centres often have a bed unit and ambulant palliative team, with some teams also serving associated municipalities. The home nursing service often has a resource nurse to provide palliative cancer care, who tends to have specialist qualifications in palliative care, and/or oncology nurses / oncology coordinators (Norwegian Directorate of Health, 2015; NOU 2017:16, 2017).

An equal level of palliative care must be offered to all patients (Norwegian Directorate of Health, 2015; WHO, 2013). However, studies have shown that elderly patients receive palliative care less frequently than younger patients (Brighi et al., 2014; Lindskog et al., 2015; Van Lancker et al., 2017). In Norway, the 'Nasjonalt handlingsprogram for palliasjon i kreftomsorgen' (Norwegian Directorate of Health, 2015) has reported challenges in achieving equality in the palliative care provided in all parts of the country, both in terms of availability and specialist content. In Western Norway, where this study was performed, many patients live a long way from the nearest hospital. The purpose of palliative care is to ensure that

patients and their families have the best possible quality of life in the last phase of life (NOU 2017:16, 2017). It is therefore important, in a Norwegian context, to explore how elderly home-dwelling cancer patients in the palliative phase and their most immediate family members, as individuals and as a family, perceive their experience with the health care service.

3 RESEARCH INTO FAMILY CHALLENGES

This study focuses on three areas in which families are challenged in cases of cancer in the palliative phase in an elderly home-dwelling family member: family relationships, family members' caregiver reactions and access to social support, and families' experiences with the health care service. This section will firstly focus on how the search strategy has been constructed in order to identify early research within these three areas. It will then present and compare earlier research concerning these three areas.

3.1 Search strategy

The first searches for research were performed in the spring of 2012 as part of the work involved in the project plan. In order to identify new relevant studies, more specific searches followed as part of the work involved in the substudies and in the comparison section of the thesis. Each time, searches were performed in the AMED, Academic Search Elite (ASE), Medline, Cinahl with full text and Psycinfo databases. The ASE database enables synchronous searches in Medline and Cinahl, but excludes the use of MeSH and truncation. Extensive synonym phrases were therefore developed for each of the search terms 'palliative care', 'cancer', 'elderly', 'family', 'relation', 'interaction', 'caregiver burden', 'social support', 'health care', 'satisfaction', and 'need' (see Appendix A). Search date ranges were limited from January 1998 to February 2019. Searches were also limited to adult persons and

to the Nordic and English languages. Throughout the project, manual searches were also performed in the reference lists of relevant articles.

3.2 Family relationships during cancer in the palliative phase

While this study was being planned, only two studies were found which had the specific objective of exploring experiences and needs in family relationships in cases of cancer in the palliative phase (Badr & Taylor, 2006; Gardner, 2008). When the study was being summarised, a further three studies had been added (Drabe et al., 2016; Fergus & Gray, 2009; Møllerberg et al., 2017). Because few studies were found with the specific objective of exploring experiences and needs in family relationships, studies with other objectives were also included (e.g. how to live with serious cancer, or how to successfully cope with living with cancer), which report findings on challenges present in family relationships in cases of cancer in the palliative phase (Bachner & Carmel, 2009; Carlander, Ternestedt, Sahlberg-Blom, Hellström, & Sandberg, 2011; Davies, Reimer, & Martens, 1990; Foxwell & Scott, 2011; James, Andershed, & Ternestedt, 2007; Kramer & Boelk, 2015; McLean & Jones, 2007; Molassiotis et al., 2011; D. W. Robinson, Carroll, & Watson, 2005; Syren, Saveman, & Benzein, 2006; Waldrop et al., 2005; Ward-Griffin et al., 2012; Zhang & Siminoff, 2003).

To be together, live a normal life and have a positive attitude to the situation is important for patients and family members at the end of life (Foxwell & Scott, 2011; James et al., 2007; Molassiotis et al., 2011). Two studies connect family solidarity with the perception of being a family (Carlander et al., 2011; Møllerberg et al., 2017). Family solidarity is also linked to successful coping and a feeling of control over the situation (Carlander et al., 2011; Foxwell & Scott, 2011; Molassiotis et al., 2011). Not all family members in Møllerberg et al's (2017) study wanted to be close to the person who was ill, which shows that the need for family solidarity can vary. Gardner (2008) has reported that patients and partners worked together to achieve a positive attitude to the situation. There also seems to be scant knowledge which

specifically describes what is important in family relationships, and how families work together to achieve what is important.

Openness about the illness, prognosis, thoughts and feelings is important if the family is to be able to handle the situation together (Fergus & Gray, 2009; Foxwell & Scott, 2011; Gardner, 2008; McLean & Jones, 2007). All studies with the specific objective of exploring close relationships show that most families do not talk to each other much about the situation (Badr & Taylor, 2006; Fergus & Gray, 2009; Møllerberg et al., 2017; Syren et al., 2006). In some families, the members have different communication preferences: some want openness and others do not (Waldrop et al., 2005; Zhang & Siminoff, 2003); this can challenge the relationships (Carlander et al., 2011). A lack of openness makes it difficult to understand each other's thoughts and feelings (Møllerberg et al., 2017) and know how to best support each other (Gardner, 2008) and can result in family conflict (Badr & Taylor, 2006; Fergus & Gray, 2009; Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2010; Waldrop et al., 2005). A range of causes for a lack of openness have been reported, including: protecting each other and oneself, maintaining a positive focus and avoiding conflict (Bachner & Carmel, 2009; Møllerberg et al., 2017; Syren et al., 2006; Ward-Griffin et al., 2012). Møllerberg et al. (2017) has reported that the families in their study played a 'secret game' to hide their concerns from each other. There also appears to be little description of how a lack of openness affects family relationships, and of how families work together to face the challenges caused by the illness when they cannot manage to talk to each other.

Fergus & Gray (2009) have reported that the behaviour of patients and their partners affects how a couple adapts to the challenges caused by the illness. Adverse behaviour in patients and family members, such as being self-centred, being unable to maintain a positive focus and avoiding talking about the illness, can result in family conflict (Badr & Taylor, 2006; Fergus & Gray, 2009; Waldrop et al., 2005). Behaviour in patients that is reported as positive

includes lending a hand wherever possible, not feeling sorry for oneself, appreciating family members' efforts, expressing needs and letting go of previous roles (Badr & Taylor, 2006; Fergus & Gray, 2009). Behaviour in partners that is reported as positive includes accommodating changes in the patient, providing suitable support and accepting the situation (Badr & Taylor, 2006; Fergus & Gray, 2009). So far, we have found no studies which focus on the behaviour of family members other than the partner.

Studies with the specific objective of exploring close relationships have reported that patients and family members must make adaptations within the relationship in order to handle the situation of cancer in the palliative phase in the family (Gardner, 2008; Møllerberg et al., 2017; Syren et al., 2006). According to Fergus & Gray (2009), challenges such as communication barriers, strategies to avoid burdening each other, and how to negotiate support have to be overcome in order to enable the couple to adapt successfully to the situation. Studies also report that a prerequisite of relational adaptation to the situation appears to be that the patient and family members develop a common understanding or opinion about the situation (Carlander et al., 2011; Fergus & Gray, 2009; Gardner, 2008). Different understandings can make it more difficult to provide reciprocal support (Gardner, 2008) and can lead to family conflict (Fergus & Gray, 2009; D. W. Robinson et al., 2005). Badr & Taylor (2006) have reported that some couples in their study who talked to each other about the quality of the relationship and discussed strategies for communication, cooperation and problem-solving functioned better together. Otherwise there appears to be scant knowledge about which relational adaptations are necessary and how the family can work together to adapt to the familial challenges caused by the cancer.

This literature review has identified areas which patients and family members regard as important and difficult in family relationships as a consequence of cancer in the palliative phase (e.g. family solidarity, openness about the situation of the illness, each other's

behaviour and relational adaptations). There is scant knowledge, and a need for more in-depth knowledge about how cancer in the palliative phase affects family relationships and how families work together to achieve what is important and overcome the difficulties in the relationships.

Studies in this literature review with the specific objective of exploring experiences and needs in family relationships have different methodological approaches. None of the studies have had a specific focus on elderly cancer patients. Only three studies have exclusively recruited cancer patients in the palliative phase (Drabe et al., 2016; Gardner, 2008; Møllerberg et al., 2017). Patients in the other studies were in both the curative and palliative phases (Badr & Taylor, 2006; Fergus & Gray, 2009). Only Møllerberg et al. (2017) has recruited patients and family members with different relational connections to the patient (e.g. the patient's partner and/or children). The other studies have exclusively recruited patients and partners. In two of the studies, the relationship of the patients and partners was as a couple (Drabe et al., 2016; Gardner, 2008). In Fergus & Gray's (2009) study some of the patients and partners were couples, and others were not. Badr & Taylor (2006) recruited patients and partners who were not connected to each other. The data collection methods in the studies also varied. Two studies collected data through individual interviews (Badr & Taylor, 2006; Drabe et al., 2016). Gardner (2008) interviewed the couples firstly together, then individually, and Fergus & Gray (2009) collected data through a mix of interviews of individuals, focus groups and couples. Only Møllerberg et al. (2017) collected data through interviews of family groups. Møllerberg et al.'s (2017) study is also the only study performed in a Nordic context.

3.3 Different family caregiver groups' caregiver reactions and social support

Studies which map family members' caregiver reactions have been performed in different illness contexts (such as frail elderly people, dementia, heart failure) (Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010; Garlo, O' Leary, Van Ness, &

Fried, 2010; Harding et al., 2015). In cancer in the palliative phase, cross-sectional studies (Hartnett, Thom, & Kline, 2016; Schrank et al., 2016; Utne, Miaskowski, Paul, & Rustøen, 2013), longitudinal studies (Lee et al., 2013; Milbury, Badr, Fossella, Pisters, & Carmack, 2013), and studies specifically related to elderly people have all been performed (B. J. Daly, Douglas, Lipson, & Foley, 2009; Garlo et al., 2010; Germain et al., 2017). Most studies have mapped connections between characteristics in the patient, caregiver and/or caregiving situation and caregiver reactions (Govina et al., 2015; H. H. Kim et al., 2016; Peters et al., 2015). Findings show, among other things, that the patient's degree of dependence and symptom burden, the caregiver's gender, age and relationship to the patient, and the number of caregiving tasks are related to caregiver reactions (Lee et al., 2013; Park et al., 2012; Yoon, Kim, Jung, Kim, & Kim, 2014). Some studies have explored the connections between caregiver reactions and social support. Most studies here report that caregiver reactions can be reduced if the family members have someone with whom to share the responsibility (Lee et al., 2013; Park et al., 2012; Shieh, Tung, & Liang, 2012). However, it is also reported that social support does not reduce caregiver reactions (Grov, Fosså, Sørebo, & Dahl, 2006).

Most studies which have charted caregiver reactions and social support have recruited one caregiver per patient, this being the person considered to be the primary caregiver (B. Given et al., 2004; Lee et al., 2013; Park et al., 2012). Family members with different relational connections to the patient, because they have various other obligations, may have different perceptions of the caregiving responsibility and access to social support (Hoffmann & Mitchell, 1998; Lowenstein & Gilbar, 2000; Stajduhar, 2013). Caregiving responsibility and access to support can also be perceived differently by family members who have the sole responsibility, compared with family members who share responsibility with several other people (Lowenstein & Gilbar, 2000). Since caregiving responsibility is often shared by several people when the patient is elderly, it seems to be important to chart and compare

caregiver reactions and access to social support among different groups of family members caring for elderly cancer patients in the palliative phase.

Only five studies were found which have compared caregiver reactions in different groups of family caregivers caring for cancer patients (B. Given et al., 2004; Y. Kim, Baker, & Spillers, 2007; Lowenstein & Gilbar, 2000; Lund, Ross, Petersen, & Groenvold, 2014; Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). One study was also found which has charted both caregiver reactions and social support (Goldstein et al., 2004); however this study does not report differences in social support between different groups of family caregivers. The studies were performed in the USA (B. Given et al., 2004; Goldstein et al., 2004; Y. Kim et al., 2007), Denmark (Lund et al., 2014; Nielsen et al., 2016) and Israel (Lowenstein & Gilbar, 2000). Only Lowenstein & Gilbar (2000) have exclusively recruited caregivers caring for patients over the age of 65. However, the patients in this study had recently been diagnosed and were in the early phase of the cancer. B. Given et al.'s (2004) study is the only longitudinal study. Four of the studies have recruited one caregiver per patient, and all found that adult children reported the most caregiver reactions (B. Given et al., 2004; Goldstein et al., 2004; Y. Kim et al., 2007; Nielsen et al., 2016). Only two studies have compared caregiver reactions in the partner and children of the same patient, and both find that spouses report the most caregiver reactions (Lowenstein & Gilbar, 2000; Lund et al., 2014). Lund et al. (2014) managed to recruit more than one family member for approximately 1/3 of 413 cancer patients in various stages of cancer. This means that there is a lack of studies which in a Norwegian context compare caregiver reactions and access to social support in various groups of family caregivers (e.g. spouse/partner, adult children, children-in-law, children/children-in-law of patients with or without a partner) caring for elderly cancer patients in the palliative phase.

3.4 Families' experiences with the health care service

A number of studies, both qualitative and quantitative, have explored patients' and/or family members' experiences and needs in their dealings with the health care service in cases of cancer in the palliative phase. Some studies have focused on the health care service in general, while others have focused more specifically on the home nursing service or medical follow-up care (Connell et al., 2010; Ewing & Grande, 2012; Funk, Allan, & Stajduhar, 2009; Janssen & Macleod, 2010; C. A. Robinson, Bottorff, McFee, Bissell, & Fyles, 2017). Some studies have had a specific focus on patients living outside cities (Devik, Hellzen, & Enmarker, 2015; Duggleby et al., 2011; Lockie, Bottorff, Robinson, & Pesut, 2010).

Five studies were found which exclusively recruited elderly cancer patients in the palliative phase and/or their family members (Devik et al., 2015; Duggleby et al., 2011; Jo et al., 2007; Wiik, Andreassen Devik, & Hellzen, 2011; Williams et al., 2018). Three of the studies, two Norwegian (Devik et al., 2015; Wiik et al., 2011) and one from Canada (Duggleby et al., 2011), have had a specific focus on patients living outside cities. Apart from the fact that the patients in Wiik et al.'s (2011) study reported that they experienced age discrimination because they were offered less advanced treatment than younger patients, the findings in these five studies do not differ from studies with a wider age composition.

It seems to be well documented, in cases of cancer in the palliative phase, that patients and family members need information but do not receive enough of it. Information is important in order to allow successful coping, reassurance and to enable patients and families to organise their lives. A lack of information results in frustration, helplessness and lack of control (Bee, Barnes, & Luker, 2008; Connell et al., 2010; Harding et al., 2012; Waldrop et al., 2012).

Many patients and family members are dissatisfied with the coordination and continuity of the health care service provided by hospitals, the home nursing service and between the various levels of the service (Funk et al., 2009; Neergaard, Olesen, Jensen, & Sondergaard, 2008).

They reported a need for a single contact person, who knows both the health care system and the family, and who can coordinate and monitor the service (Harding et al., 2012; Hunstad & Svindseth, 2011; Neergaard et al., 2008). It is worth noting that studies which have evaluated the experiences of patients and family members receiving palliative care show that these people help to provide reassurance, continuity and coordination, which reduces the family members' caregiver reactions (Ciemins, Brant, Kersten, Mullette, & Dickerson, 2014; Jack, Mitchell, Cope, & O'Brien, 2016). When the patient is living at home, access to services from the hospital, GP and home nursing service when they need it is important, but this is something that patients and family members often struggle to obtain (Bee et al., 2008; Funk et al., 2009; Funk et al., 2010; Sandsdalen et al., 2015). If essential services are available 24 hours a day, this provides reassurance, particularly for the family members (Funk et al., 2009). The staff members' personality, or the quality of the relationship between the patient, family members and staff members (such as respect, friendliness, trust, patience and empathy) is also important (Funk et al., 2009; Funk et al., 2010; Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003; Neergaard et al., 2008; Sandsdalen et al., 2015). Patients and families living outside cities report similar findings, except for the fact that long distances are considered to be the cause of reduced availability and flexibility (Devik et al., 2015; Duggleby et al., 2011). Long and tiring journeys for cancer follow-up care are also particularly reported in these studies (Duggleby et al., 2011; Lockie et al., 2010; Wiik et al., 2011). Another finding worth noting is that many patients and family members have little trust in their GP's expertise in terms of cancer follow-up care, and prefer to contact the hospital if they have any problems (Aabom & Pfeiffer, 2009; Halkett, Jiwa, & Lobb, 2015; Neergaard et al., 2008). Many family members also struggled to receive support for their own needs. Time for themselves is the biggest need, but respite is difficult to obtain because the family members are unwilling to

leave the patient or their care in the hands of others (Funk et al., 2010; Harding & Higginson, 2001).

An important principle of palliation is to view the patient and family members as a single unit. However, it was not possible to find studies which explored how their experiences with the health care service affected the family unit. The studies included in this literature review have collected data through interviews with individuals and/or focus groups with homogeneous groups of patients, family members and/or health care personnel, and mainly reported findings involving the individual perspectives of patients and/or other family members.

Furthermore, some studies contain suggestions about how experiences with the health care service challenge the family unit. The need of family members to be involved in the health care service's follow-up care of the patient is well documented (Harding et al., 2012; Hunstad & Svindseth, 2011; C. A. Robinson et al., 2017; Williams et al., 2018). Many patients also report a need for the health care service to involve close family members (McSkimming et al., 1999; Sandsdalen et al., 2015). The family members in the study by McSkimming et al. (1999) illustrate the family perspective when they report that their need to be involved is because decisions are being made which also affect their lives. Close family members can also be an important resource in terms of helping the patient to communicate and remember information (Speice et al., 2000). Other studies have reported that patients and family members may have different preferences concerning the content, timing and manner in which information is presented (Bee et al., 2008; Connell et al., 2010). It is also reported that patients and family members may have different needs in terms of service from the home nursing service. The patients would prefer to manage without help (Devik et al., 2015; Funk et al., 2009), while the family members report that the home nursing service eases their caregiving responsibilities (Funk et al., 2009; Grande, Todd, & Barclay, 1997; Totman, Pistrang, Smith, Hennessey, & Martin, 2015). The way in which the health care service is

organised also challenges families. For example, inadequate flexibility in terms of organising check-ups around available transport provision and/or family members' jobs means that family members have to disrupt their own plans in order to drive the patient, which becomes an additional burden for the families (Connell et al., 2010; Duggleby et al., 2011). The literature review illustrates that experiences with the health care service can challenge the family unit. This may for example be in terms of family involvement, information exchange and help from the home nursing service.

In summary, the literature review shows that in the three areas family relationships, family members' caregiver reactions and access to social support, and families' experiences with the health care service, the family as a unit is challenged by cancer in the palliative phase. We need more knowledge in order to have an understanding of what patients and family members perceive as important and difficult in family relationships, and how they work together to handle the challenges involved in cancer in the palliative phase in family relationships. More knowledge is also required about how caregiver reactions and access to social support is perceived by family members with different relational connections to the patient. We also need more knowledge about how experiences with the health care service are perceived, not just by patients and family members as individuals, but by the family as a unit. The research presented has mainly been performed on a sample in which patients have had a broad age composition and in which family members have been the patient's partner. Further research into these themes should therefore specifically explore the experiences and needs of elderly patients and of family members with different relational connections to the patient.

4 FAMILY SYSTEMS, CAREGIVER REACTIONS AND SOCIAL PROVISION

There are several theoretical perspectives illustrating the family as a system (Benzein et al., 2012; Kaakinen & Hanson, 2015; Østergaard & Konradsen, 2016). In this study, Wright &

Leahey's (2013) book 'Families and Nurses' was selected as the main source of inspiration. Wright & Leahey are nurses and family therapists, and with the aid of theory, research and practice, have been working to develop a theoretical framework since 1984. Theories about family members' caregiver reactions have been taken from several sources (Braun et al., 2007; B. Given et al., 2004; Zaider & Kissane, 2009). In terms of social support, Weiss's (1974) theory on social provisions was used, because it focuses on the fact that different relationships provide different types of support. The selected theoretical perspectives were used in planning and implementing this study.

4.1 Family systems theory

The theory considered to have had the greatest influence on the understanding of families is the systems theory (Kaakinen & Hanson, 2015; Wright & Leahey, 2013). Among other things, the family systems theory has been used as a theoretical framework in Nordic studies into chronic illness, weight-loss surgery and cancer in the palliative phase (Bylund, Benzein, & Persson, 2013; Møllerberg et al., 2017; Årestedt, Persson, & Benzein, 2014).

The systems theory has been developed within the field of sociology, and Von Bertalanffy is considered to be the originator of the theory (Kaakinen & Hanson, 2015; Wright & Leahey, 2013). According to Von Bertalanffy (1950), p 143, a system can be defined as: '... a complex of interacting elements P₁, P₂... P_n'. The interaction assumes that the elements are in relation to each other (Von Bertalanffy, 1950). Transferred to families, the systems theory makes it possible to focus on the family as a whole, and to observe relationships, interactions and reciprocity between members, and between the family and the illness, which cannot be studied when focusing on the individual. Observations of family members' interactions tend to provide a more complete explanation of how individual members of the family work (Kaakinen & Hanson, 2015; Lundsbye, 2010; Wright & Leahey, 2013).

Systems have a hierarchical structure, in which the family as a system is subordinate to a greater suprasystem (such as the health care service), and is composed of many subsystems (such as mother and father, mother and child) (Lundsbye, 2010; Wright & Leahey, 2013). Families perform their function in the subsystems, and in each subsystem the individual family member has different powers, functions, roles, tasks and talents. An important function performed within the subsystems is to help and support each other when facing challenges caused by illness (Wright & Leahey, 2013).

Systems are defined by their ties or boundaries, which determine what is within and what is outside of a system (Lundsbye, 2010; Wright & Leahey, 2013). The ties help to protect the family and individual members of the family, and can be loose or rigid to varying degrees. Where a tie sits on the 'loose-rigid' continuum says something about how the family works and its chances of adapting to change. For example, very rigid ties mean that members hold onto what they are used to, have limited interaction with their surroundings and do not accept help and support. The relationship between a sick family member and the family member providing care creates special ties because they share thoughts, experiences and information, and make decisions, which can make it more difficult for other family members to provide help and support (Kaakinen & Hanson, 2015; Lundsbye, 2010; Wright & Leahey, 2013). Open systems have a continuous exchange of help and support with their surroundings, and undergo development and change to a greater degree (Lundsbye, 2010).

The system is continuously changing, but at the same time is slow to change, which means that families need patterns of continuity, identity and stability which can be preserved, while new patterns for behaviour are being developed (Lundsbye, 2010; Wright & Leahey, 2013). When there is a change in one member of the family, such as an illness, all the members of the family and the family as a whole will influence and be influenced in attempts to regain equilibrium or balance (Lundsbye, 2010; Wright & Leahey, 2013). The family's support

functions are initiated, and the family's resources and the strains both on individuals and the family system will decide whether the situation is perceived as disruptive, and how well the members of the family will manage to support each other. How the family experiences the interaction with the health care service also plays a part (Wright & Leahey, 2013).

The interaction between the members of a family in terms of solving problems and challenges is often called family functioning (Kaakinen & Hanson, 2015; Wright & Leahey, 2013).

Wright and Leahey (2013) have divided family functioning into practical and emotional functioning. Practical challenges are easier to cope with successfully than emotional challenges, and concern routines and responsibilities in daily life, which often have to be redistributed in cases of illness. Interactional patterns are the main elements of emotional functioning, and concern communication and problem-solving strategies, perceptions and alliances in the family (Wright & Leahey, 2013). Families may have positive and negative functioning, in which each individual and family unit can encourage or hamper the health, well-being and functioning of other members and the family unit (Benzein et al., 2012; Wright & Leahey, 2013).

Relationships and interactions between members of a family can have varying degrees of symmetry and complementarity (Lundsbye, 2010; Wright & Leahey, 2013). A complementary relationship consists of a giver and a receiver, where the person initiating an action is in a hierarchical position over the person following the action (e.g. mother and child, family and health care service). A symmetrical relationship is between two people of equal status (e.g. a couple), in which both reserve the right to initiate action, criticise the other person, give advice, etc. Both types of relationship and interaction can be suitable and positive in terms of health, depending on context and needs, but in other situations an imbalance can affect the quality of the relationships. For example, whether the patient only expects to be helped, and whether the caregiver only helps without getting anything back (e.g. gratitude).

The relationship between the family and health care service is largely complementary, with the health care service contributing help for the family. However, the health care service imposes particular rules on the family, which gives the greater system stability, but which can make change difficult, reduce options and weaken the family's ability to use its own resources (Wright & Leahey, 2013). One example could be check-ups and examinations at the hospital, which tend to take place during the day, when the patient's family is at work and it is difficult for them to help and support the patient.

Linear and circular thinking can help to understand the reciprocal interaction in systems.

Linear thinking is cause – effect ($A \rightarrow B$), while circular thinking involves an awareness that the interactions are reciprocal ($A \rightarrow B \rightarrow A \rightarrow B \dots$) (Wright & Leahey, 2013). Both ways of thinking and interacting with each other can be useful in helping families to achieve their purpose. Linear thinking can for example be of assistance in organising daily life (e.g. at 16:00 it is dinner time, which means that everyone must be home by 16:00). But linear thinking can sometimes have an obstructive effect in families, because the members of the family then do not take into consideration how their behaviour affects other members.

Circular thinking can promote community, cooperation and options that help families adapt to change due to illness. Families often need help to move from linear thinking into a more reciprocal and systemic thinking (Wright & Leahey, 2013).

4.2 Caregiver reactions

Caregiving responsibility for a family member with cancer in the palliative phase imposes considerable stress on family members (C. Given et al., 1992; Grov & Dahl, 2010; Stajduhar, 2013). A number of factors has been shown to contribute to this stress: the stage of the cancer and medical condition of the patient, approach of the health care service, family members' physical and mental health, quality of social relationships (e.g. access to resources, cooperation with the patient), the family members' experiences with caregiving responsibility

and the family's situation (e.g. function and conflicts) (Braun et al., 2007; B. Given et al., 2012; Grov & Dahl, 2010; Zaider & Kissane, 2009).

How the family members perceive the caregiving responsibility has been explored and described from various perspectives, such as stress, coping, needs, quality of life and specific caregiver reactions (B. Given et al., 2004; Grov, Dahl, Fosså, Wahl, & Moum, 2006; Hagedoorn et al., 2008; Wadhwa et al., 2013). The negative stress of caregiving is often referred to as the caregiver burden (Bastawrous, 2012; B. Given et al., 2004; Montgomery, Gonyea, & Hooyman, 1985). Montgomery et al. (1985) have also used the term 'family burden'. Interest in the concept of burden developed in the 1950s and 1960s, primarily in relation to studies of family members caring for mentally ill patients. Burden is often divided into objective and subjective burden of care. Objective burden of care refers to specific caregiving duties (such as medical tasks and help with daily activities), while subjective burden of care refers to the caregiver's experience and perceptions of the caregiving responsibilities, and assessments of their role as caregiver (Bastawrous, 2012; Braun et al., 2007; Montgomery et al., 1985; Nijboer et al., 1998).

The term 'caregiver burden' is multidimensional, and there is no recognised definition (Bastawrous, 2012; Hoffman, 2008). B. Given et al. (2004), who use the term 'caregiver reaction', have the following definition:

'a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social role, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfil (p. 1106)'.

In other words, caregiver reactions is a perception that the situation is exceeding the caregiver's available resources. Available resources can come from the caregiver themselves, informal and formal support (Braine, 2016). As mentioned earlier, the informal support

depends on the quality of the family relationships and the family's functioning (Braun et al., 2007; B. Given, Given, & Kozachik, 2001; Zaider & Kissane, 2009).

4.3 Social Provisions

The term 'social support' is complex and multidimensional (Cutrona & Russell, 1987; Luszczynska, Pawlowska, Cieslak, Knoll, & Scholz, 2013), and has several definitions (Cutrona & Russell, 1987). Uchino (2009) has defined social support as: 'the functions that are provided by social relationships (p. 238)'. The perception of social support is subjective (Bondevik, 1997; Cutrona, Russel, & Rose, 1986; Cutrona & Russell, 1987), and even if a person is receiving a great deal of support, the support is not necessarily perceived positively (Luszczynska et al., 2013; Uchino, 2009).

Weiss' (1974) theory about 'social provisions' illustrates the human need for a variety of social relationships and the support provided by these relationships. Weiss (1974) identified six categories of social provisions, which must all be present if an individual is to feel suitably supported and avoid isolation and stress. These are: attachment, social integration, reassurance of worth, opportunity for nurturance, guidance and reliable alliance. In this study, our focus will be on the first four categories. The reason why two have been left out will be justified in the 'method' section. Several of the social provisions can be received from the same person. Different conditions can be required for different types of provisions, so there is therefore a tendency for different relationships to offer different kinds of support (Russell, Cutrona, Rose, & Yurko, 1984; Weiss, 1974). Attachment provides a feeling of reassurance, security, well-being and belonging, and most often tends to be provided by a spouse or partner, but also by friends and family members. A lack of attachment can result in loneliness and emotional isolation (Russell et al., 1984; Weiss, 1974). Social integration tends to be provided by a network of friends who share interests, concerns, social activities, information, service, and who develop a shared understanding of experiences. Absence of relationships

which provide social integration can lead to social isolation (Russell et al., 1984; Weiss, 1974). Reassurance of worth means acknowledging a person's skills and abilities, and tends to be provided by colleagues and friends (Russell et al., 1984; Weiss, 1974). Opportunity for nurturance differs from the others in that the person here is the provider of support (Russell et al., 1984; Weiss, 1974). This factor is linked to feeling that other people's well-being depends on oneself, such as responsibility for one's children and partner (Cutrona & Russell, 1987; Russell et al., 1984; Weiss, 1974).

4.4 Comparison of the concepts

The perspectives presented in relation to the family systems theory, caregiver reactions and social provisions have been selected because they complement each other in ways which satisfy the objective of this study. A key element of the study is family caregiving. The perspectives presented show that social provisions have an effect on family members' caregiver reactions. When family members provide help and support for the patient, this can trigger negative reactions. On the other hand, support for family members who provide care can reduce family members' caregiver reactions. The family systems theory illustrates how help and support are exchanged in families affected by illness, and how caregiver reactions can hamper a family's opportunities for handling the situation, and for helping and supporting each other. The three perspectives therefore go together, and can help to illustrate different aspects of family caregiving.

A key aspect of the family systems theory is family relationships. These are relationships which 'bind' the members together into a family system, and which ensures that there are reciprocal interactions in the system. The perspectives of social provisions and caregiver reactions show that help and support are exchanged in relationships, and that the quality of the relationships affects how well patients and family members are able to help and support each other (Braun et al., 2007; Wright & Leahey, 2013; Zaider & Kissane, 2009).

The family systems theory has a systemic perspective and is concerned with interactions and processes in the family. The perspectives of social provisions and caregiver reactions are individually oriented and illustrate individual family members' experiences and needs. According to the family systems theory, individual members of the family's reactions and needs can trigger reciprocal interactions in the family system. In-depth knowledge about individual family members' experiences and needs in terms of caregiver reactions and access to social provisions, on which the family systems theory does not go into detail, may therefore help to improve the understanding of what happens in family relationships in cases of illness. Furthermore, in-depth knowledge about what happens in family relationships in cases of illness could help to improve understanding of interactions and processes present in families when help and support are exchanged and caregiver reactions experienced, which could help to increase knowledge about individual family members' experience of social provision and caregiver reactions. The systemically and individually oriented perspectives mean that we can study the same phenomenon from different angles, systemically and in the light of the individual, which means that the three perspectives complement each other in this study.

5 AIMS

The overall aim of this study was to develop new knowledge about what is important and difficult in families as a consequence of cancer in the palliative phase in an elderly home-dwelling family member. The thesis consists of three substudies, two with a qualitative approach (I, III), and one with a quantitative approach (II) (see Table 1).

Table 1 - Title, aim and data collection methods in the three papers

	Title	Aim	Method
Paper	A Valuable but Demanding Time. Family Life During	To explore what elderly cancer patients and their family members experience	Qualitative approach

I	Advanced Cancer in an Elderly Family Member	as important and difficult in close family relationships during the palliative phase, and how they interact and communicate about these challenges	Family group interviews Content analysis
Paper II	Caregiver reactions and social provisions among family members caring for home-dwelling patients with cancer in the palliative phase: A cross-sectional study	To assess and compare caregiver reactions and social provisions among different family caregiver groups caring for home-dwelling elderly adult cancer patients during the palliative phase	Quantitative approach Descriptive statistical tests (Frequencies, Mann-Whitney U-tests, T-tests)
Paper III	'Non-palliative care' – A qualitative study of elderly cancer patients' and their family members' experiences of the health care system	To explore what elderly home-dwelling cancer patients in the palliative phase and their close family members, as individuals and as a family, experience as important and difficult when interacting with health services	Qualitative approach Family group interviews Content analysis

6 METHODS

6.1 Design

Patients with cancer in the palliative phase tend to have a short life expectancy. This means that the families are in a vulnerable phase of life, and it was ethically important not to put more strain on the families than necessary. For this reason, a cross-sectional study including both qualitative and quantitative methods was found to be suitable for the objective of the study. Various methodological approaches were chosen, because they provide different types of knowledge, which can result in richer and more authentic descriptions of complex phenomena (Foss & Ellefsen, 2002; Moule, Aveyard, & Goodman, 2017; Polit & Beck, 2018).

6.2 Sample

6.2.1 Inclusion and exclusion criteria

The participants in the study are families with an elderly home-dwelling family member with cancer in the palliative phase. Family life has ethnic and cultural variations (Wright & Leahey, 2013). Therefore, to avoid major variations in the sample, only ethnic Nordic families were recruited. Elderly people are a heterogeneous group, and in the western world tend to be defined as those over the age of 65 (McWilliam, Ward-Griffin, Oudshoorn, & Krestick, 2008; Ministry of Health and Care Services, 2018; Thompson, 2010), so this study also used that definition. Cognitive decline and reduced hearing can make participation in group interviews difficult (Smithson, 2008). The participants therefore also had to be capable of giving their informed consent, and able to participate in discussions involving several people. Additional diagnoses are common in elderly cancer patients (Dahl & Grov, 2014; Grov et al., 2010b), and therefore did not constitute an exclusion criterion. The patients had to have been informed that the cancer was not curable. In terms of both patients and family members, we ideally wanted to recruit both genders. Further inclusion criteria for family members were: ≥ 18 years old, and with various relational connections to the patient (e.g. partner, child, child-in-law, grandchild).

6.2.2 Recruitment procedure

Recruiting participants to studies in the field of palliative care (Chen et al., 2014; Hanson et al., 2014; Jordhøy et al., 1999), and to family group interviews (Beitin, 2008; Donalek, 2009), can be difficult. For this study, participants were recruited to all three substudies simultaneously. Small groups of 2-5 participants were selected because the topic was sensitive, the families are in a vulnerable situation (Hyden & Bulow, 2003; D. L. Morgan, 1996), and because it could be difficult to find a time for interviews which suited everyone in the family (Uphold & Harper, 1986). Families are also complex systems (Donalek, 2009;

Morris, 2001; Sterling & Peterson, 2005), which means that it can be difficult to observe the interactions and processes in large groups (D. L. Morgan, 1996; Munday, 2006).

The families were recruited from Fransiskushjelpen in Oslo and from hospitals and municipalities in three counties in Western Norway: Rogaland, Hordaland and Sogn og Fjordane. The municipalities were first contacted via the resource nurse network for palliative cancer care, former students in the post graduate education programme Palliative Care at the former Sogn og Fjordane University College, or the home nursing service, in order to identify which municipalities had suitable patients. Chief municipal executives, heads of ward, out-patient clinic and palliative team departments and the head of Fransiskushjelpen were thereafter provided with information about the study by phone and/or email, and asked to assist with recruitment. Those who expressed a willingness to assist with recruitment appointed a contact person, who was provided with information about the study, the recruitment procedure and inclusion/exclusion criteria.

Relevant patients and family members were informed and provided with an information letter about the study (see Appendix B). Families who were interested in participating, or who wanted more information, sent a signed consent form (Appendix C), or gave the contact person permission to give the PhD candidate their telephone number. The PhD candidate then contacted the families by telephone, and if the families were willing to participate, agreed a time and place for an interview. In order to achieve a broad range in the sample, the PhD candidate discussed with the family's contact person which family members would participate in the interview, but the final decision was left to the family.

6.2.3 Final sample

A total of 33 families expressed willingness to participate in the study. Of these, 7 families pulled out before the interview because the patient's medical condition had worsened. No

families pulled out during or after the interview. The final sample consisted of 26 families, a total of 86 participants. Of the patients, there were equal numbers of women and men (13/13). Each family unit consisted of the patient and at least one family member, on average three family members. Table 2 shows the participants' average age and the family members' relationship with the patient. A total of 15 patients lived with their spouse (one spouse did not participate due to health problems). A total of 9 patients lived alone, and 2 lived with one of their children.

Table 2. Sociodemographic Characteristics of the Participants

Characteristic	Mean	Range
Family Members' age (N=86)		
Patients	79	(65-92)
Spouses	73	(55-84)
Sons	49	(33-56)
Daughters	46	(27-62)
Sons-in-law	63	
Daughters-in-law	45	(34-53)
Grandchildren	21	
Sisters	65	
Characteristics	N	%
Relationship of the Family Member to the Patient (N=60)		
Wife	10	16
Husband	4	7
Son	11	18
Daughter	26	43
Son-in-law	1	2
Daughter-in-law	6	10
Grandchild	1	2
Sister	1	2
Children's Marital Status (N=37)		
Married	24	65
Unmarried	13	35
Family Members' Educational Level (N=60)		
High school or above	31	52
Below high school	29	48
Family Members' Employment Status (N=60)		
Employed full-time or part-time	45	75
Retired, sick leave or unemployed	15	25

Table 3 provides an overview of the diagnoses of patients and their spouses.

Table 3. Clinical Variables of the Patients and their Spouses

Cancer types	Patients		Spouses	
		Other diseases		Other diseases
Lung	7	Cardiovascular diseases	10	4
Prostatic	6	Polymyalgia	1	
Breast	1	Hearing impairment	4	1
Colon	6	Musculoskeletal diseases	9	6
Amyloidosis	1	Mental diseases	1	
Gynaecologic	1	Cerebral diseases	4	2
Mole	2	Renal failure	1	1
Bone marrow	1	COPD, asthma	3	
CML	1	Diabetes	2	2
Myelomatosis	1	Vision impairment	1	
Unknown	1	Crohn's disease	1	

In terms of Grov's (2014) division of the palliative phase into early, late and terminal phases (page 20), most of the patients at the time of interview were in the late palliative phase. A total of 8 patients were receiving palliative tumour-directed treatment, the majority through chemotherapy in tablet form. Of the 26 patients, 20 patients were receiving help from the home nursing service. Of these, 12 patients were receiving help with personal hygiene, 5 were supervised and 20 had their weekly pill organiser filled. A total of 14 families had a home help doing housekeeping. Geographically, 2 families lived in large towns, 1 in a small town, 5 in medium-sized municipalities, and 18 families lived in municipalities with less than 5,000 inhabitants. A total of 14 patients had a journey time of more than 1 hour to the nearest hospital.

6.3 Qualitative approach (substudies I and III)

When the objective is to explore the content in social phenomena, as it is perceived for those involved within its natural context, a qualitative approach is suitable (Malterud, 2012; Moule et al., 2017; Polit & Beck, 2017). The research strategy in the qualitative approach is to obtain

detailed descriptions which provide variation and in-depth insight into the phenomenon being studied (Kvale & Brinkmann, 2009; Polit & Beck, 2017). The qualitative method is suitable for family research, since it provides the opportunity to study multiple experiences and perspectives, which are often present in families (Mehta et al., 2009; Sterling & Peterson, 2005; Wright & Leahey, 2013; Åstedt-Kurki, Paavilainen, & Lehti, 2001).

6.3.1 Family group interviews

Family group interviews are an expedient data collection method when the purpose is to collect data about families (Norlyk, Haahr, & Hall, 2016; Sakellariou, Boniface, & Brown, 2013; Åstedt-Kurki & Hopia, 1996). Families consist of individuals with both individual and shared perceptions, experiences and needs. Family group interviews will therefore provide data at various levels (Eggenberger & Nelms, 2006; Mehta et al., 2009; Sterling & Peterson, 2005). Interactions present between participants in the family group interview will also provide data about family dynamics (Braybrook, Mróz, Robertson, White, & Milnes, 2017; Donalek, 2009; Norlyk et al., 2016; Sakellariou et al., 2013).

Family group interviews are a little-used data collection method, and there is limited literature about family group interviews as a method (Bjørnholt & Farstad, 2014; Braybrook et al., 2017; Donalek, 2009; Polak & Green, 2016). Like other family researchers (Eggenberger & Nelms, 2006; Åstedt-Kurki et al., 2001), we have therefore turned to the focus group methodology for inspiration. Family groups and focus groups have clear differences. The participants in focus groups tend not to know each other earlier on (Krueger & Casey, 2009), while the participants in family group interviews know each other intimately, and have a shared past, present and future (Eggenberger & Nelms, 2006; Åstedt-Kurki & Hopia, 1996).

In both individual and group interviews, interaction between the participants, including the interviewer, promotes data production. (Bjørnholt & Farstad, 2014; Graneheim & Lundman,

2004; Polak & Green, 2016; Racher, Kaufert, & Havens, 2000). In family group interviews, the participants know each other, and in addition can challenge and correct each other's narrations, and help each other to remember. Data which are produced in family group interviews thereby become richer and more valid, provided that the data collection method is appropriate in relation to the objective of the study (Bjørnholt & Farstad, 2014; Norlyk et al., 2016; Sakellariou et al., 2013).

How well the researcher manages to create an atmosphere of friendliness, respect and openness will influence on what the participants will share (K. J. Daly, 2007; Kvale & Brinkmann, 2009; Åstedt-Kurki & Hopia, 1996). Group interviews also require the ability to facilitate group processes (Gilliss & Davis, 1992; Sim, 1998), and handle contentious topics (Donalek, 2009; McClement & Woodgate, 1998). The PhD candidate is a qualified gestalt therapist, and as a teacher of nursing students, has extensive experience of guiding group work. In order to allow them to get to know her and create a safe arena for the interview, the PhD candidate chatted informally with the participants before the interview began. The participants were then given an introduction to the objective of the study, the structure of the family group interview in terms of duration and breaks, their rights, the protection of their anonymity and their right to break off the interview, as well as any further information they required. They were also asked whether they consented to the interview being audio-recorded. In order to ensure that the participants were aware that they could talk about individual experiences and needs, it was explained that both individual and shared perceptions, experiences and needs are present in families, and that the objective was to hear both.

A genogram drawing helps to ensure an awareness of relationships and interactions (Wright & Leahey, 2013), therefore most of the interviews started with a genogram drawing. At some interviews, one or more members of the family were so eager to start talking that the genogram drawing was postponed until there was a natural break, or until the end of the

interview. The genograms included between four and five generations, and contained data about: gender, age, marital status (e.g. married, divorced, single), deceased family members, children's geographical distance to the patient's home and the family members' work situation. Friends, colleagues and/or neighbours who were so close that the families considered them part of the family, were also drawn into the genogram. The PhD candidate found that the genograms interested the participants, and contributed to a good atmosphere and openness in the interviews.

An interview guide based on research and family systems theory was used (Appendix D). The interview guide acted as a thematic checklist in the interviews, ensuring that important topics were mentioned. A pilot interview was performed, and the interview guide did not change. Nor was the interview guide changed at a later stage in the data collection period. After the opening question: 'What is important for you now, with ... being ill?' was asked, the interviews were mostly unstructured, with many of the topics in the interview guide arising spontaneously. From time to time, follow-up questions were asked in order to explore topics in depth. In order to collect data about family relationships, interactions and reciprocity, circular questions were asked (e.g. 'what do you ... think about what ... has just said?') within cognitive, emotional and behavioural domains (Wright & Leahey, 2013). Clarifying questions to validate what was said (Kvale & Brinkmann, 2009): 'did you mean... now?' were asked during the interview, both by the PhD candidate and participants.

The atmosphere in the interviews was for the most part friendly and caring. Both individual and shared perceptions, experiences and needs were present, as well as agreement and disagreement when the participants supported or challenged and corrected each other's statements. In two interviews, the atmosphere was strained for a while, and it was clear that the topics which triggered the tension were well known to the participants. In some interviews, the patient took rest breaks and allowed the family members to continue with the

discussion. However, some patients needed the help of the family members to express what they thought, which shows that some of the patients had reduced cognitive capacity. Other literature has reported similar findings, and claims that family group interviews may be less of a strain on frail elderly participants (Morris, 2001), and allow participants with communication problems to be heard (Arksey, 1996; Kendall et al., 2009; Sakellariou et al., 2013).

The interviews were conducted wherever it suited the families, with all of the interviews being conducted in the patient's home, mainly because of the patient's frail state of health. According to Larossa, Bennett, and Gelles (1981) the significance of close relationships is apparent most of all in the home. The home is therefore considered to be a good place in which to hold the interviews. Audio recordings were made of the family group interviews, in order to allow the PhD candidate to concentrate on the topic, interactions and non-verbal communication present in the interview. Audio recordings can be played numerous times and ensure proximity to the data (Kvale & Brinkmann, 2009). The duration of every interview was between 90 and 120 minutes.

6.3.2 Transcription

The transcription of the research interviews involves decontextualisation, with the verbal discussion being abstracted and converted into written text. Some of the emotions in the discussion (such as irony, body language, tone of voice, intonations and breaths) were lost, which means that the transcription does not fully reproduce the interview discussion (Kvale & Brinkmann, 2009). This study explores sensitive topics, and the PhD candidate wished to obtain the underlying opinions in the families' narrations. In order to convey the nuances in the discussions, and the interaction between the participants, the interviews were transcribed verbatim wherever possible (Graneheim & Lundman, 2004; Kvale & Brinkmann, 2009). Pauses in the discussion are marked with, interruptions marked with INTERRUPTED,

forceful statements with capital letters, and emotions are written in brackets, such as (crying) (Kvale & Brinkmann, 2009). Quotations which were used in the articles have been reproduced in a more coherent way, which means that repetitive and unnecessary words, as well as interruptions and the representation of emotions, were omitted (Kvale & Brinkmann, 2009).

The interviews were transcribed immediately. The PhD candidate transcribed the first 15 interviews. The last 11 interviews were transcribed by a contracted person, who by signing the contract consented to abide by the duty of confidentiality. Transcribing the interviews oneself ensures the maximum congruity between the interview discussion and the transcription text (Bird, 2005), and provides the opportunity for making notes in the margin about tone, mood etc. remembered from the interview discussions, which also starts the analysis process (Kvale & Brinkmann, 2009). To ensure that the last 11 interviews were transcribed correctly, these were listened to carefully after transcription, which also provided the opportunity to make notes on mood in the margin in the written document, and to initiate the analysis process.

6.3.3 Data analyses

The qualitative data were analysed through qualitative content analysis, as described by Graneheim and Lundman (2004). Qualitative content analyses are suitable for analyses of complex and sensitive phenomena (Elo & Kyngas, 2008; Graneheim, Lindgren, & Lundman, 2017), and are therefore suitable for this study. Qualitative content analysis involves the interpretation of textual data (Elo & Kyngas, 2008; Graneheim & Lundman, 2004). The analysis may be made at two levels: manifest and latent. Manifest content analyses focus on the visible structure, and keep the interpretation close to the text. Latent content analyses involve an interpretation of the underlying meaning of the text. The focus is on the deeper structures (such as silence, signals, laughter, posture), and relational aspects of the text (Elo &

Kyngas, 2008; Graneheim et al., 2017; Graneheim & Lundman, 2004). The interpretation of the text is therefore deeper and more abstract with latent content analyses (Graneheim et al., 2017; Graneheim & Lundman, 2004), and latent content analyses may be regarded as a hermeneutic interpretation (Graneheim et al., 2017).

The researcher tends to begin with manifest analyses, and continues by searching for the latent content (Graneheim et al., 2017), and this was also the procedure in this study. The transcribed interview texts were firstly divided into two analysis units, suitable for the two research questions (I, III). Each unit was then analysed separately using the same method. The method was inductive or data-driven (Graneheim et al., 2017), and started by reading the entire text several times in order to become familiar with the content, and to pick out important aspects of the text (Elo & Kyngas, 2008; Graneheim & Lundman, 2004). The entire text was then divided into meaning units, which were coded. The objective of the study was kept in mind when performing the division into both meaning units and coding. The codes were then brought together on a coding form, and the meaning units sorted under the codes. The codes were then analysed in relation to similarities and variations, and grouped into categories. Graneheim and Lundman (2004) write that categories mainly highlight the manifest content, and that topics can be regarded as an interpretation of the latent content of a text. A topic is described as: ‘... a unifying “red thread” running through several categories that brings meaning to a recurrent topic or experiences and its various manifestations (p. 32)’ (Graneheim et al., 2017). In order to capture the latent content of the text, descriptions in each category were critically analysed, examined and compared with other categories, meaning units and the entire text. The following question was in focus at all times: ‘what is taking place in the family relationships here?’ With the aid of this procedure, a main topic and several topics became apparent for each of the two qualitative substudies (I, III).

6.4 Quantitative approach (substudy II)

A descriptive cross-sectional study is a survey which by using questionnaires gathers data on the frequency of variables, such as incidents, emotions, attitudes, etc. in various groups (Moule et al., 2017; Polit & Beck, 2017). The questionnaires in this study was handed out after the end of the family group interview. The family members completed the questionnaires in the presence of the PhD candidate, which made it possible to ensure that all the questions were answered. The family members were instructed in how to read and complete the questionnaires, and informed that there were no right or wrong answers. If the participants needed help, for example because it was difficult to understand a question, the PhD candidate helped to explain the question and complete the questionnaires. A few of the spouses needed some help, and the PhD candidate read all the questions out to two of the spouses.

6.4.1 Measurement

Two questionnaires with a total of 40 questions: CRA (24 items) and SPS (16 items) were handed out (Appendices E and F). Demographic conditions were also surveyed (Appendix G). The latter contained questions about age, gender, marital status (e.g. never been married, married/cohabiting, widow/widower). The questionnaire also contained questions about the connection to the patient (e.g. partner, child, child-in-law), geographical distance to the patient, education (e.g. lower secondary school, vocational college, university college), job situation (e.g. on sick leave, working full-time, receiving retirement pension, home-maker), and whether they were receiving any form of government benefit (e.g. sickness benefit, disability pension, retirement pension).

6.4.2 The Caregiver Reaction Assessment (CRA)

Various questionnaires have been developed to survey caregiver reactions (Groß & Dahl, 2010; P. L. Hudson & Hayman-White, 2006; Tanco et al., 2017). In this study, we have

chosen to use the CRA, which was developed by C. Given et al. in 1992. The CRA has been widely used to survey caregiver reactions in people with caregiving responsibility for cancer patients in the palliative phase, has been psychometrically tested and validated (Deeken et al., 2003; Grov & Dahl, 2010; P. L. Hudson & Hayman-White, 2006; Tanco et al., 2017), in countries including Norway (Grov, Fosså, Sjørebø, et al., 2006; Grov, Fosså, Tønnessen, & Dahl, 2006). The psychometric properties have been reported as satisfactory and with the same dimensions as the original version.

The CRA consists of 24 questions which cover 5 dimensions: self-esteem (7 questions), lack of family support (5 questions), financial impact (3 questions), impact on daily schedule (5 questions) and impact on health (4 questions) (C. Given et al., 1992). The family members' score is graded on a 5-point Likert scale with the format: 1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree. The total score of each dimension forms the average score for the questions associated with that dimension (from 1.0 to 5.0). The purpose of one of the dimensions, self-esteem, is to measure positive experiences with caregiving responsibility, which means that a high score indicates a low caregiver reaction. The four other dimensions measure negative experiences with caregiving responsibility, which means that a high score indicates a high caregiver reaction.

6.4.3 The Social Provisions scale (SPS)

In order to survey family members' access to social support, the SPS (Russell et al., 1984) was used. The SPS has previously been used in studies of cancer care and care for the elderly (Cutrona et al., 1986; Lyyra & Heikkinen, 2006), in countries including Norway (Bondevik, 1997; Grov, Fosså, Tønnessen, et al., 2006).

The SPS originally consisted of 24 questions, which covered 6 dimensions: attachment, social integration, opportunity for nurturance, reassurance of worth, a sense of reliable alliance and the achievement of guidance. Due to a high correlation between the dimensions 'reliable

alliance' and 'guidance', and the 4 other dimensions, these 2 dimensions were removed from the revised version of 16 questions, as recommended by Russell et al. (1984). SPS is constructed as a 4-point Likert scale, and the response options are: agree strongly = 4, agree = 3, disagree = 2, and disagree strongly = 1. A high score indicates a high level of social support. Bondevik (1997) psychometrically tested the Norwegian version of the SPS. The factor analysis was confirmed, and supports the factor structure which was proposed in the revised version of the SPS.

6.4.4 Statistical analysis

The quantitative data were analysed using the SPSS version 24 (SPSS Inc., Chicago, IL). In order to compare family members with a different relational connection to the patient, the following family groups were constructed: spouses and children/children-in-law. Since no one has performed such sub-analyses before, this is an exploratory study and we have no exact outcome targets on the extent of the changes we can expect. It is therefore difficult to perform an exact power calculation. However, to enable ourselves to indicate how many family units we needed to recruit, we performed a power calculation. We set the α -value at 0.05 with a strength of 0.80 and the ability to identify differences, Cohen's $d=0.80$ (Sloan, 2003) (<http://www.danielsoper.com/statcalc/calc47.aspx>). The calculation shows that we needed 24 participants per family group. We therefore assumed that we needed to recruit 25-30 family units, and we managed to recruit 26 family units, with an average of 3 family members per patient. Unfortunately, despite our wish to have 24 in each comparison group, we were unable to recruit a sufficient number of sons and children-in-law to construct separate groups for these. Instead, in order to explore whether the caregiver reactions and social support of children and children-in-law were affected by whether the patient had a spouse or not, we constructed the following two groups: children/children-in-law of patients with a spouse and children/children-in-law of patients without a spouse.

Tests were performed in order to clarify whether data were normally distributed, and the values were found to be satisfactory. However, since the sample was small, we performed both parametric (t-tests) and non-parametric (Mann-Whitney U-tests) tests. Apart from question 11 on the CRA comparing spouses and children/children-in-law, all the p-values were consistent in the group comparisons. Because we primarily wanted to compare our findings with studies which have used the CRA, and because the majority of these report mean and SD, we have also reported these values and the corresponding p-values from t-tests. In addition, we performed a Spearman's rho correlation analysis of the dimensions of the SPS and CRA. The significance value was set at $p < 0.05$ and all tests were two-sided.

6.5 Ethical considerations

The study was performed in line with the basic principles of the Declaration of Helsinki and the Norwegian Act on medical and health research (Health Research Act, 2008). Permission to perform the study was obtained from the Regional Committees for Medical and Health Research Ethics (REC, 2011/1731a) (Appendix H).

The basic principles of the Declaration of Helsinki with regard to participation, information, consent and consideration of particularly vulnerable groups have been important in this study. Valid consent means that the consent is voluntary, informed, expressed and documented (Ruyter, Førde, & Solbakk, 2014). All the participants in the study were over the age of 18, and capable of giving their consent, which is a prerequisite of informed consent (Ruyter et al., 2014). The information letter (Appendix B) contained information about objective, methods (such as use of audio recordings), anonymization and voluntariness, as stipulated by the requirement for written information (Ruyter et al., 2014). In order to safeguard voluntariness, the PhD candidate had no first-hand contact with the participants, and no reward for participation was offered (Ruyter et al., 2014). Expressed and documented consent was

safeguarded by getting all the participants to sign a declaration of consent, with the families and PhD candidate each retaining a copy (Appendix C) (Ruyter et al., 2014).

Participants' vulnerability must always be evaluated when planning and performing research (Moule et al., 2017; Ruyter et al., 2014). Cancer patients in the palliative phase and their families are considered to be a vulnerable group (Chen et al., 2014; Hanson et al., 2014; Sivell et al., 2015); their time is valuable, participation in research is burdensome, and the patients themselves will not benefit from the knowledge which is produced (Bloomer, Hutchinson, Brooks, & Botti, 2018; Ruyter et al., 2014; Sivell et al., 2015). Studies have shown that using words such as death and the palliative phase in the information letter can be perceived as burdensome (Gjertsen, 2009), and can unexpectedly reveal diagnoses and prognoses (Hickman, Cartwright, Nelson, & Knafl, 2012); therefore the terminology 'people living with cancer' was used in the information letter. It has also been claimed that not researching vulnerable groups is unethical, since the objective of research is to obtain knowledge and promote quality in the health care service (Bloomer et al., 2018; Sivell et al., 2015). In order to reduce the risk of harm, the initial contact was made by health care personnel who knew the families and were able to evaluate the families' vulnerability (Hickman et al., 2012). Follow-up support if necessary was also arranged for patients and family members who might find participation burdensome, from the contact personnel who assisted with recruitment (Ruyter et al., 2014). The families were provided with information about this in the information letter and at the end of the interview. Bloomer et al. (2018) show in a summary article that dying patients value participation in research and consider their contribution to be important, particularly if it can help others. Studies also claimed that participation in research can have unintentional therapeutic effects (Bloomer et al., 2018; Donalek, 2009; Sivell et al., 2015). Many of the families in the study mentioned after the interview that it had been good to participate, with no one expressing that it had been uncomfortable. One family said that

they had agreed to participate because it gave them an opportunity to talk to each other about the situation.

There is a risk with research interviews that in striving to create an open and trusting atmosphere, the interviews risk becoming too intimate, and that the participants reveal more than they really want to (Haahr, Norlyk, & Hall, 2014; Kvale & Brinkmann, 2009). The risk may be greater in family group interviews than in individual interviews, since an unexpected and unwanted revelation from one participant could cause other participants to feel obliged to respond or contribute (Larossa et al., 1981). Some researchers claim that family group interviews can bring family conflicts to the surface (Norlyk et al., 2016; Sakellariou et al., 2013; Wright & Leahey, 2013). Others also claim that the families will be focused on taking care of each other and the family's self-image, and that for this reason, family conflicts rarely come to the surface (Fog, 2004; Morris, 2001). Throughout the interviews, the PhD candidate tried to be sensitive, to safeguard the participants' boundaries and integrity and recognise all viewpoints. Some participants were occasionally emotionally moved, and in two families topics arose which were clearly contentious. In contrast to individual interviews, it tended to be the participants themselves who supported and/or protected each other emotionally, often by changing the subject. Sometimes the PhD candidate asked the families whether they wanted to change the subject.

Long questionnaires can be burdensome for families in vulnerable life phases (Hickman et al., 2012). The questionnaires in this study contained 40 questions, which took around 15 minutes to complete. The questions which were asked could be perceived as emotionally burdensome, for example because the family members become aware of how burdensome their caregiving responsibility is, or that they lack social support. The questionnaires were completed while the PhD candidate was still present, and no family members expressed that the questions were emotionally burdensome to answer.

A final ethical consideration concerns confidentiality. Qualitative research in particular provides detailed descriptions, which makes the anonymization of data and participants particularly important and challenging (Kaiser, 2009; Ruyter et al., 2014). This confidentiality applies both to the storage of data (e.g. audio recordings, consent forms, completed questionnaires, trace files), and the anonymization of transcribed text and articles on publication (Kaiser, 2009; Kvale & Brinkmann, 2009; Ruyter et al., 2014). Audio recordings and trace files are kept locked in a safe, separate from each other and from the transcribed interviews. When transcribing the interviews, all recognisable data were removed or replaced with pseudonyms. When publishing findings, essential details were changed in order to ensure that the presentation could not be traced back to specific families (Kaiser, 2009).

7 MAIN FINDINGS

7.1 Paper I

Main topic: ‘a valuable but demanding time’, illustrates that important and difficult factors were present simultaneously and affected each other. Important factors: ‘ensuring a positive final time together’ was both an objective and a strategy for the families. By spending time together and encouraging each other, the difficult aspects could be sent to the background. The patient and family members thereby supported each other. Difficult factors: ‘avoiding tension and conflict’, illustrates how the patient’s dependence challenged family relationships, both emotionally and practically. The topic is divided into two sub-topics. ‘Balancing different needs’ illustrates that patients’ and family members’ various new needs could sometimes be difficult to understand and for others to accommodate, which could thereby trigger tensions and conflicts in the relationships. The second sub-topic: ‘distribution of responsibility and tasks’ illustrates that new responsibilities and new tasks could be difficult

to discuss and distribute in the families. The third topic: ‘concealing thoughts, feelings and needs’, illustrates how patients and family members interacted in order to ensure a positive final time together, to avoid burdening each other and generating tensions and conflicts in the relationships. Instead of talking openly to each other, patients and family members observed and interpreted each other in order to find out how each reacted, and how best to help and support each other. This strategy mostly worked well, but occasionally it became difficult to understand and accommodate each other’s various needs, subsequently causing tension and conflict in the family relationships.

7.2 Paper II

The patients’ dependence brought about caregiver reactions for the closest family members. On the CRA, the comparison of various family groups’ caregiver reactions showed significant differences in 3 out of 5 dimensions. Spouses reported significantly more disruption in terms of ‘disrupted schedule’ than children/children-in-law. In the ‘lack of family support’ dimension, children/children-in-law and children/children-in-law of patients without a spouse scored significantly higher than spouses. Children and children-in-law of patients without a spouse also scored significantly higher than children and children-in-law of patients with a spouse in ‘impact on health’. On the SPS, we found significant differences in 2 out of 4 dimensions. In ‘nurturance’, spouses reported significantly higher scores than children and children-in-law of patients without a spouse. In ‘attachment’, children/children-in-law of patients with a spouse scored significantly higher than children/children-in-law of patients without a spouse.

7.3 Paper III

Main topic: ‘ “Non-palliative care”– health care services in the palliative phase not tailored to family needs’, means that the families did not find that they were receiving suitable help and

support from the health care service. Three topics were identified. The first topic: 'exhausting cancer follow-up care' illustrates that both tumour-directed palliative treatment and journeys to the hospital for follow-up care were too exhausting for the frail patients. Journeys in shared taxis, which involved longer journey times, were particularly tiring. For this reason, cancer follow-up care at hospital was terminated for some patients. At the same time, the GP was not always an alternative for the families. Some had doubts about the GP's expertise, and for some patients it was also too exhausting to visit the GP. The second topic 'a cry for family involvement' illustrates that the patients either did not want or did not have the capacity to be in charge of contact with the health care service, and had therefore delegated this responsibility to the family members. The family members therefore needed to be involved in the health care service's follow-up care of the patient, particularly in the exchange of information regarding the patient's health situation. The hospitals also did not seem to have systems for involving the family. A lack of knowledge of the health care system, different needs within the family (e.g. concerning 'transfer of responsibility' and information), and other obligations (e.g. job) made it difficult for the family members to navigate their contact with the health care service. The third topic: 'fragmented care' illustrates the families' perceptions of continually meeting unfamiliar personnel. Instead of this, the families needed to get to know the staff, so that their assistance could be suitable, predictable and continuous, and so that confidence and trust could be established in the relationships. Because the assistance from the home nursing service was perceived to be fragmented and unpredictable, the families tried to manage without it for as long as possible. Cancer nurses were an exception: a person who was available to the patient and family over a long period, and a resource who could help the families to navigate through the health care system, provide information and act as someone to talk to in a difficult period. When there were conflicting

needs for help from the health care service, this could cause tensions in the family relationships.

7.4 Comparison of results

On the whole, the results show that cancer in the palliative phase in an elderly home-dwelling family member not only challenged patients and family members as individuals, but also groups of family members and the family as a whole. A particularly important finding seems to be that family relationships were challenged. As a consequence of the cancer's challenges, patients and family members found that they had a variety of new needs which were difficult to communicate openly in the family. A lack of openness about these needs sometimes made it difficult to understand and accommodate each other's needs, giving rise to tensions and conflicts in the relationships. Relational challenges could therefore be an obstacle to a positive final time together, make it difficult for the family to help and support each other, and difficult to seek and receive help from the health care service.

8 DISCUSSION

8.1 Discussion of findings

This study has examined what is important to and difficult for families who experience cancer in the palliative phase in a home-dwelling elderly family member. The findings show that it was important, but difficult for the families to have a positive final time together, that family members with different relationships with the patient could experience the caregiving responsibilities and access to social support differently, and that the health care services' help and support options were not always suitable for the families' needs. An overall interpretation of the findings is that cancer in the palliative phase is challenging to family relationships. In cases of cancer in the palliative phase, families may need help and support to understand the

reciprocity in the family relationships, to handle relational challenges in the family system and to find good ways of cooperating that help the family to adapt to the challenges caused by the cancer.

8.1.1 Cancer in the palliative phase initiates reciprocal interactions in family relationships

The findings show that patients and family members were reciprocally affected by each other's reactions and needs. This shows that cancer in the palliative phase in a home-dwelling elderly family member not only affects patients and family members as individuals, but is a family matter that affects the family as a system. For example, both patients and family members said that a positive attitude in other family members made it easier for them to handle the situation (I). Patients and family members also tried to hide their thoughts, feelings and needs to avoid burdening each other (I, III), which meant that they had to observe and interpret each other to find out how to provide the best help and support (I). A third example is the patients' increasing dependence on their family members, which meant that the family members had more tasks and new responsibilities (I, III), which could be stressful to all parties (I, II, III). Other studies conducted on cancer in the palliative phase report that a positive attitude is important, and that it can be difficult to talk openly about the situation of the illness (Foxwell & Scott, 2011; Gardner, 2008; Molassiotis et al., 2011). Other studies have also reported that patients and family members experience changes in tasks and responsibilities (Gardner, 2008; Molassiotis et al., 2011; Syren et al., 2006), and that family members find caregiving responsibilities stressful (B. Given et al., 2004; Y. Kim et al., 2007; Lund et al., 2014). These studies have otherwise not problematized how patients' and family members' reactions and needs reciprocally affects members of the family. Møllerberg et al. (2017) found that the families in their study changed their patterns of interaction and played a 'secret game' to avoid hurting and disturbing each other. In this study it is perhaps more accurate to say that the members of the family 'concealed' (hid) than to describe their

behaviour as a 'secret game', but both perspectives show that the families wanted to protect each other. Two other studies have found that the patients' behaviour, e.g. not feeling sorry for themselves and clearly expressing their needs, helped the partner to adapt to the situation (Badr & Taylor, 2006; Fergus & Gray, 2009), which can be compared to our findings mentioned above. Fergus & Grey (2009) in particular report findings that highlight how the patient's and the partner's different reactions and needs reciprocally influence the other's. Fergus & Gray found behaviour in both patients and partners that hindered or promoted the other's behaviour and how they adapted to the situation together. The latter mentioned study uses a psychological perspective and the findings are discussed in relation to stress theory, not the family systems theory. The findings in this study were sometimes contradictory, possibly because data were collected through family group interviews where it can be difficult for the participants to report the negative aspects of each other's behaviour.

It is also worth noticing that the way the health care service were organised initiated reciprocal interactions between patients and family members. One example is transport with shared taxis to and from the hospital for families who were unable to drive themselves. Shared taxis, meaning that several patients were transported at the same time, entailed long and tiring journeys for patients who lived a long distance from the hospital (III). For the family members, the shared taxis led to worry and a guilty conscience, and some chose to drive the patient themselves, which could be challenging to organise, for example in relation to work (III). Long and tiring journeys to the hospital for cancer follow-up have been reported before (Duggleby et al., 2011; Lockie et al., 2010), and the present study also supports another Norwegian study with the same findings (Wiik et al., 2011). However, these studies did not problematize how the journeys to the hospital had a reciprocal effect on the family relationships.

Findings from the three substudies support and complement each other in the conclusion that there is a reciprocal influence between the patient's and family members' reactions and needs. For example, the patients' spouses reported significantly more disrupted schedule in the CRA in the quantitative substudy (II). The two qualitative sub studies (I, III) show that patients, children and children-in-law saw that the spouse/parent was busy, worried about them and therefore tried to help and support them as best they could. A comparison of the findings therefore shows that individual family members' caregiver reactions affected the patient and other family members, which corresponds with the conclusion of other theories (Balducci & Dolan, 2016; Northouse, 2012; Zaider & Kissane, 2009).

8.1.2 A lack of awareness of the reciprocity of interactions challenges family relationships

According to the family systems theory, the reciprocal influence in the family system means that events, for example illness on the part of a family member, throws the family system off balance. In order to re-establish or create new balance in the family, all members of the family influence and are influenced by each other (Lundsbye, 2010; Wright & Leahey, 2013). The wish of the families in this study of hiding their concerns and needs to avoid burdening each other and to ensure that their final time together was as positive as possible (I), can, in light of the family systems theory (Wright & Leahey, 2013), perhaps be seen as strategies to preserve continuity and identity at the same time as trying to re-establish equilibrium in the family system. However, the study shows that everyone was worried about each other regardless (I, III), that it was difficult to discuss the distribution of tasks and responsibilities (I, III), that the family members were tired sometimes (I, II and III) and that there were sometimes tensions and conflicts in the relationships (I, III).

The relational challenges seem to be connected to the fact that the patients and family members sometimes had different needs that could be difficult for others to understand and accommodate. For example, the patients needed to manage on their own as much as possible,

while the family members needed to be in control and know that the patient was receiving the necessary help (I, III). Sometimes, the family members needed respite and rest, while the patient needed their immediate family around them and did not want help from the home nursing service (I, III). Different preferences as regards information about the patient's health could also be challenging to the family relationships (I, III). Children and children-in-law had different challenges than the spouse in relation to the caregiving responsibilities (e.g. childcare responsibilities, work) (I, III), which was also reflected in findings of significant differences between spouses and children/children-in-law in the CRA and SPS (II). Carlander et al. (2011) report that patients' and family members' different preferences for open communication about the challenges caused by the illness can challenge family relationships. It has also previously been documented that conflict seems to be connected to an inadequate understanding of each other's situation (Badr & Taylor, 2006; Fergus & Gray, 2009; Kramer & Boelk, 2015). According to the family systems theory, families as a system comprise many subsystems (Lundsbye, 2010; Wright & Leahey, 2013), (e.g. the mother-father subsystem, or the mother-child subsystem). In each subsystem, the individual has different powers and different functions, roles, tasks and capability (Wright & Leahey, 2013). Different needs are therefore common in families. However, this study shows that the cancer led to new and different needs, which could be difficult to understand and accommodate and which could thereby lead to tensions and conflicts in the relationships (I, III).

Why different needs are sometimes difficult to understand and accommodate in this study seems to be due to the fact that it was difficult to talk to one another about needs, because it was so important to have a positive focus and not burden each other (I). The strategy of maintaining a positive focus therefore did not always seem to contribute to re-establishing equilibrium in the family system. The fact that a desire to maintain a positive focus (Badr & Taylor, 2006; Gardner, 2008; Zhang & Siminoff, 2003) and not burden each other can prevent

openness has been documented before (Fergus & Gray, 2009). Fergus & Gray (2009) also found that difficulties with speaking openly to each other influenced couples' ability to solve problems together and support each other. This can be compared with our findings that inadequate openness led to different needs becoming difficult to understand and accommodate. Although the participants in Fergus & Gray's (2009) study were female breast cancer patients and their male partners, meaning that the sample is therefore not entirely comparable to our sample. Despite this, the findings in both studies show that an inadequate understanding of each other's situation can make it more difficult for families to adapt to the challenges caused by cancer.

The patients' and the family members' wishes to conceal and hide their concerns and needs from each other, leading to difficulties with understanding and accommodating each other's different needs, seem to be connected to a lack of awareness of reciprocity in family relationships. More light can be shed on this through the family systems theory's linear and circular views on causal connections. According to Wright & Leahey (2013), linear thinking about causal connections in families can have an adverse effect on family functioning, because the members of the family do not consider how their own behaviour affects others in the family. The patients and family members in this study thought that by concealing and hiding their concerns and needs from each other, they would avoid burdening each other (I), which reflects a linear cause → effect way of thinking. As shown by the findings in substudy 1, patients and family members were aware that others were trying to hide their concerns and needs from them, but were not as aware that others also were observing and interpreting them in order to find out how they were doing. With the exception of Foxwell et al. (2011), who report that partners were aware of each other's attempts to hide their concerns and did not find it helpful, we have not found other studies that report similar findings.

According to Wright & Leahey (2013), awareness that interaction in family relationships is reciprocal can promote community, cooperation and the family's opportunity to adapt to changes as a result of illness. Awareness of this reciprocal interaction can promote an understanding that it can be important to talk with each other to understand each other's different reactions and needs, to find ways of helping and supporting each other. An understanding of the reciprocity of relationships and interactions can thereby help the family to adapt to cancer in the palliative phase. For example, understanding that different members of the family can have different preferences with regard to receiving information about the disease, can help the family to find strategies so that those who want lots of information can have it, while at the same time protecting those who want to know less. As regards open communication, most studies in the context of cancer in the palliative phase have focused on openness about the disease and prognosis (Foxwell & Scott, 2011; McLean & Jones, 2007; Molassiotis et al., 2011). In the same way as Badr & Taylor (2006) and Fergus & Gray (2009), this study also shows that it is important to be open about individual reactions and needs and relational challenges in order for families to be able to adapt to the challenges caused by the disease, or to arrive at new equilibrium in the family system.

8.1.3 Families may need the health care service to treat them as a system

Health care policy goals have established that the health care service must develop help and support services that are adapted to the needs of patients and family members, to ensure that the patients can stay at home as much as possible and that immediate family members can cope with the caregiving responsibilities (Ministry of Health and Care Services, 2013, 2015; Norwegian Directorate of Health, 2017; NOU 2011:17, 2011). Thus far, the discussion has shown that awareness of reciprocity in family relationships can help the family to adapt to the challenges caused by the cancer. The following discussion will address families' need for the

health care service to treat them as a system and to be offered help and support on the basis of the family system's needs.

Examples of findings that highlight the family's need to be treated as a system include the family members' need to be involved in the health care service's follow-up treatment and care of the patient. Many of the patients had given their family responsibility for managing information regarding their own health situation. Despite this, the hospitals mostly informed only the patients, and it was difficult for the family members to become involved. As a result, the families become insecure and uncertain about how to handle the situation of the illness at home (I, III). Findings also show that taking over responsibility for the exchange of information, as well as the fact that the family members had different preferences in relation to how much information they wanted about the patient's health situation, could lead to tensions in the family relationships (III). Since the goal is for the patient to spend as much time as possible at home, it seems important for the health care service to treat families as systems. The health care service must invite the whole family for a discussion and explore not only the patient's needs, but also what the family members and family unit need in relation to the exchange of information. The fact that communicating with the health care service is challenging to elderly people (Balducci & Dolan, 2016; Sparks & Nussbaum, 2008; Thompson, 2010; Williams et al., 2018), and that immediate family members want and miss being involved in the cancer follow-up treatment and care (Harding et al., 2012; Hunstad & Svindseth, 2011; C. A. Robinson et al., 2017) has been reported in previous studies. However, we have found no other studies that problematize findings in light of the family as a system.

Patients and family members often found that the health care service interventions offered, particularly respite care services and help with personal hygiene from the home nursing service, were not helpful and declined the offers. This may be because the help offered was not adapted to the needs of the family system. Substudy II shows that the family members

found caregiving responsibilities to be stressful; reports have been made of disrupted schedule, inadequate family support and a negative impact on own health. The qualitative substudies (I, III) show that children and children-in-law were concerned that the spouse/parent would become exhausted, which is a sign that the families could have needed respite care interventions. A comparison of the findings from the three substudies could possibly contribute to a better understanding of why the families often declined respite care interventions such as the home nursing service, respite care in nursing homes and help from children and children-in-law (I, III). For example, the spouses had high scores on a single item on the dimension of self-esteem (measuring positive caregiver reactions) on the CRA: 'I am very grateful that I am able to care for...' (4.79 ± 0.43 , highest possible score 5.0), and high on the dimension 'opportunity for nurturance' on the SPS (14.57 ± 1.40 , highest possible score 16.0). 'Opportunity for nurturance' is about knowing that someone depends on you, and this can help to create a sense of meaning (Russell et al., 1984; Weiss, 1974). According to Weiss (1974) 'opportunity for nurturance' had a positive effect on self-esteem. These two scores can thereby be interpreted to mean, as shown by the qualitative findings, that the spouses genuinely wanted and found it valuable to spend time with and help and support the patient (I, III). Findings also show that the patients wanted to manage as much as possible on their own (I), and preferred only their spouse to help them with intimate tasks (I, III). Nor did the families want a constantly changing set of strangers coming into their home (III). The lack of staff continuity (Duggleby et al., 2011; Funk et al., 2009; Jo et al., 2007; Milberg et al., 2012), and the patient's reluctance to have strangers helping them with personal care tasks have been reported earlier (Devik et al., 2015; Funk et al., 2009).

The family systems theory explains how much help and support the family wants to receive in connection with illness on the basis of theory on systems' ties and boundaries as more or less permeable to outside help (Lundsbye, 2010; Wright & Leahey, 2013). It seems easier to

explain the findings of this study in light of the reciprocal influence in family relationships. The family members knew that the patient did not want help from the home nursing service, and spouses in particular were unable to accept health care that went against the patient's wishes (III). At the same time, many spouses wanted to help and support the patient in this difficult life situation (I, III). Other studies have also reported that patients and family members are ambivalent to respite care interventions (Funk et al., 2009; Funk et al., 2010). Respite care, which is highlighted as an important measure to reduce the next of kin's caregiver reactions in the new guide for next of kin (Norwegian Directorate of Health, 2017), therefore seems to be a health care service measure that is not adequately adapted to the needs of the family system. Instead, this study shows that emotional concerns are experienced as more stressful to the family members than the practical tasks associated with the caregiving responsibilities (I). This is in line with the family systems theory (Wright & Leahey, 2013). Such concerns are not resolved through respite care interventions, but through information and knowledge about what could happen, how to handle problems (including relational challenges), where to get help and support and through access to a cancer nurse (III). Other studies have also found that information is important in order for patients and family members to cope successfully and feel confident when dealing with the disease (Bee et al., 2008; Connell et al., 2010; Harding et al., 2012).

The goal of palliative care is to reduce suffering and promote the quality of life of both patients and the family (World Health Organization, 2017). This is in line with this study's finding that the families want their final time together to be as positive as possible (I). At the same time, the study shows that cancer in the palliative phase was challenging to the families. To help families achieve the goal of a positive final time together, it seems to be important for the health care service to treat families as a system. The relational challenges resulting from cancer in the palliative phase should be the focus of the health care service's endeavours to

help and support the family unit. The health care service should, when needed and desired, be able to offer guidance and support so that families can find ways of interacting that help them to adapt to the situation.

According to Wright & Leahey (2013), families may need help to move from a linear to a more circular understanding of interactions and relationships in the family system. In a review article, Östlund and Persson (2014) demonstrate that family system nursing interventions can help families to adapt to the situation of caring for a sick relative. The articles shows that families' understanding, capacity and mastery of the situation increased, they cared more for each other and increased their emotional wellbeing in addition to improving their interaction with each other. This seems to demonstrate that health care service interventions that focus on the family as a system can help families to adapt to the challenges caused by cancer.

8.2 Methodological considerations

The concepts of reliability and validity have been used in both qualitative and quantitative research to highlight and demonstrate the quality of the research, but many people have claimed that the concepts are unsuitable for qualitative research (Elo et al., 2014; Graneheim & Lundman, 2004; Polit & Beck, 2017). In this study, reliability and validity will therefore be used in relation to the quantitative substudy (II). To highlight and demonstrate the quality of the two qualitative substudies (I, III) Lincoln and Guba's concept of 'trustworthiness' (Lincoln & Guba, 1985) will be used. Trustworthiness is frequently used in studies that make use of qualitative content analyses (Elo et al., 2014; Graneheim & Lundman, 2004).

8.2.1 Combination of different methods

Using different methods in studies of the same phenomenon can result in richer and more authentic descriptions of complex phenomena (Foss & Ellefsen, 2002; Moule et al., 2017; Polit & Beck, 2018). Family phenomena are complex (Donalek, 2009; Morris, 2001; Sterling

& Peterson, 2005), and using both the qualitative and the quantitative methods can lead to richer perspectives on families (Ganong, 1995; Åstedt-Kurki et al., 2001). By only using questionnaires, for example, the data would be limited to the selected questions set out in the forms. By combining questionnaires with qualitative interviews, the data will include nuanced and rich descriptions of the topics the participants believe it is important to communicate, but which the questionnaires do not necessarily address. Combining different methods is also well-suited in studies that want to explore different aspects and/or several groups at the same time (Polit & Beck, 2017). By only choosing qualitative methods for gathering data, there will be little opportunity to compare groups, which is possible when using standardised questionnaires. Methodological considerations regarding the qualitative substudies (I, III) will be discussed first, followed by methodological considerations relating to the quantitative substudy (II).

8.2.2 Trustworthiness of qualitative studies

Lincoln and Guba (1985) have proposed four alternatives for assessing the trustworthiness of qualitative research: ‘credibility’, ‘dependability’, ‘conformability’ and ‘transferability’.

These four concepts are connected and interdependent (Elo et al., 2014; Graneheim & Lundman, 2004; Polit & Beck, 2017). It is not clear whether Lincoln and Guba intended for the four concepts to always be used at the same time (Morse, 2015), but all four will be used in this study.

Credibility refers to the confidence in how well the data address the intended objective, and entails an assessment of whether the sample, data collection method, interview guide questions and the saturation of data are suitable (Elo et al., 2014; Graneheim et al., 2017; Graneheim & Lundman, 2004). I would argue that the sample of this study was expedient, see section 6.2.3) because the family structure varied (e.g. the number of family members, gender, age, marital status), the families were recruited from four different counties and because the

patients had different cancer diagnoses. This contributed to a heterogeneous sample and variation of data. The development and testing of the interview guide is described in section 6.3.1. The saturation of data is affected by the number of participants (Elo et al., 2014). The sample consisted of 26 families, who gave rich and detailed descriptions, and the final interviews did not result in new insight. Family group interviews as a method of collecting data are described in more detail in section 6.3.1. The family group interviews produced detailed descriptions of the participants' individual and common perspectives, and of the interactions and processes relating to the objective of the study.

The reflexivity of the researchers must also be considered, because it may affect the research process (Elo et al., 2014). As nurses, the PhD candidate and the supervisors all have prior understanding. The PhD candidate has worked in cancer care, one of the supervisors has conducted research in the field of cancer care, and the other two in elderly care. All of them also have personal experience as members of their own families (K. J. Daly, 2007; Sterling & Peterson, 2005). The researcher participates in the knowledge production (Malterud, 2017; Moule et al., 2017; Polit & Beck, 2017). The PhD candidate therefore wrote reflection notes on own preconceptions before starting the data collection process. In addition, the PhD candidate's interview technique was evaluated immediately after each interview, when listening to the audio recordings and when transcribing the interviews. The tone of voice, whether the participants were given sufficient time to answer the questions, interruptions and how the questions were asked were among the aspects studied. The goal was for the interviews and the data to reflect the participants' experiences and needs to the greatest possible extent.

Dependability refers to whether the participants' stories are credible over time and under different conditions. It is therefore important, as described above, to make thorough references to the recruitment procedure and the characteristics of the sample in order to be

able to assess the transferability of the results (Elo et al., 2014; Graneheim & Lundman, 2004; Polit & Beck, 2017). The credibility of the data is also about how successful the PhD candidate was in creating a friendly and open atmosphere during the interviews. The strategies employed to achieve this are described in the method section (see section 6.3.1). At the end of each interview, the PhD candidate summed up the conversation, gave the participants the opportunity to comment on and correct understanding, and this strengthens the credibility of the data (Elo et al., 2014). Since this study was completed, a new guide for next of kin has been published (Norwegian Directorate of Health, 2017) and the Coordination Reform (Ministry of Health and Care Services, 2009) has been well established in the health care service. These factors may mean that the health care service's follow-up care of families has been improved recently, and that families now experience their encounters with the health care service differently from the families in this study.

Conformability refers to the objectivity, that is, the potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning (Elo et al., 2014; Polit & Beck, 2017). In line with Elo et al's (2014) suggestions, the PhD candidate was responsible for the analysis and was followed up closely by the supervisors. The whole team (the PhD candidate and supervisors) met several times to discuss the adequacy of the analysis and possible additions to codes, categories and topics that emerged.

Transferability refers to whether findings can be transferred to other situations or groups (Elo et al., 2014; Graneheim & Lundman, 2004; Polit & Beck, 2017). It is therefore important to report on the analysis process and provide a clear description of the context, culture, sample and characteristics of the participants (Elo et al., 2014; Graneheim et al., 2017; Graneheim & Lundman, 2004). The analysis process is described in section 6.3.3. The sample characteristics and the context of the study are discussed above. All the patients in this study were 65 years old or older. The findings can therefore primarily be generalised to families

with elderly cancer patients in the palliative phase. The findings will probably have transfer value to families with elderly patients with diagnoses such as strokes and advanced cardiopulmonary disease. Families with younger cancer patients might have various other commitments that can impact their experience of the illness, as discussed in section 8.1.2. The families in this study were largely recruited from the rural areas of Norway. Findings that concern long distances to hospitals can therefore probably not be transferred to families in more urban areas. Family life and family processes vary with ethnicity and culture, and it is therefore possible that the findings cannot be transferred to countries outside the Nordic countries.

To ensure transferability, the results must be reported systematically and accurately and show the connection between the results and the data (Elo et al., 2014; Graneheim & Lundman, 2004). In line with Elo et al. (2014), the findings in the articles (I, III) are presented with quotes from different families to demonstrate the connection between data and results. The use of quotes also allows the reader to look for alternative interpretations (Graneheim & Lundman, 2004).

8.2.3 Strengths and limitations of the qualitative studies

Family group interviews as a data collection method is one of the strengths of this study and has contributed to an improved understanding of what patients and family members see as important and difficult in family relationships when a family member has cancer in the palliative phase. Many of the qualitative findings did not emerge through analyses of the manifest content of the transcripts, but through analyses of the latent content, i.e. how the patient and the family members talked to each other and their behaviour. It is difficult to achieve such findings through individual interviews, which is also pointed out in literature (Norlyk et al., 2016; Polak & Green, 2016). One possible weakness of family group interviews as a data collection method is that the participants can withhold information to

protect each other (for example the patient), which can result in limited insight into sensitive issues and conflicts (Norlyk et al., 2016; Polak & Green, 2016; Sakellariou et al., 2013). In this study, the withholding of information also contributed to important data and results.

The use of co-moderators who can observe the dynamics of the group is common in focus group interviews (Krueger & Casey, 2009; D. L. Morgan, 1996). Because the patients' health situation could change quickly, the interviews had to be carried out immediately. Having two persons participate in all the interviews would have been too demanding in terms of resources. This can be seen as a weakness in the data collection. To guide the PhD candidate and check that the PhD candidate registered the dynamics between the interview participants to a sufficient degree, the supervisor co-moderated one of the interviews. The conclusion was that the co-moderator's observations did not add new data. The PhD candidate had previous experience of qualitative interviews and formal qualifications in gestalt supervision; in addition, the family groups were small, which may have made it easier to observe their dynamic.

Although this project applies a wide definition of family, the staff was only able to recruit family members connected by blood or marriage. This could be because elderly people usually have a biological family or because biological families are more common in rural areas in Western Norway. It is also possible that the personnel who assisted with recruitment only asked biological families. Early in the recruitment phase it became clear that some of the contact persons who assisted with recruitment thought that the patients had to be married. To clear up this misunderstanding, the recruitment criteria were clarified in more detail.

Few of the families in our sample expressed any major relational challenges. The personnel who recruited the families may have refrained from asking and, thereby, prevented vulnerable and stressed families from participating (Hickman et al., 2012). As participation in research is

voluntary, it is also possible that families with more challenges chose not to participate. We must therefore be cautious about transferring the findings to families in similar situations.

This is a cross-sectional study. A longitudinal study with repeated interviews could perhaps have led to a richer body of data. However, since the participants were patients in the palliative phase, we assumed that it could be difficult to organise repeated interviews.

Repeated interviews can also be exhausting for the participants and are therefore ethically challenging.

8.2.4 Strengths and limitations of the quantitative study

One of the strengths of this study is that it compares different groups of family members, which few studies have done in relation to cancer in the palliative phase. One of the limitations of cross-sectional studies is that we cannot establish causal connections between the variables studied (Moule et al., 2017). A longitudinal procedure would probably have been able to draw some conclusions on changes in caregiver reactions and social provisions over time, which could have made it possible to suggest causal connections. Most of the family caregivers had experience of caregiving responsibilities over time, and we assume that their scores on the CRA and SPS were based on experience accumulated over time, even if the time of reference in the questionnaire was 'right now'.

When *questionnaires* are reliable, it means that they are consistent and stable from one person to the next, provided that the phenomenon that is being studied has not changed. The validity of questionnaires is concerned with how well the forms measure the phenomena we want them to measure (Greenstein, 2006; Moule et al., 2017; Polit & Beck, 2017). It is however, never possible to define the exact validity of a questionnaire, because the phenomena studied are abstract, and we do not know their correct values (Greenstein, 2006; Polit & Beck, 2017). It is common to use psychometric tests to determine questionnaires' reliability and validity.

This has been done in a Norwegian context for both questionnaires (Bondevik, 1997; Grov, Fosså, Tønnessen, et al., 2006). In order to carry out a psychometric analysis using these forms, we would need a sample size of up to 150 participants (Altman, 1991; Polit & Beck, 2017), and our study's sample is not large enough for that. Persson and Sundin (2008) have carried out a psychometric test of the Swedish version of the CRA. It is interesting that the participants in open comments, analysed qualitatively, reported the lack of one aspect (concerns) and only partial coverage of one aspect (positive experiences). This questions the content validity of the CRA and the authors reported that the CRA had to be further developed. Our findings (I) show that members of the family were worried about each other, and that the emotional challenges were more difficult to handle than the practical ones. Worries thereby seem to be part of family members' negative caregiver reactions.

Internal validity concerns whether the *sample* is representative of the population studied, and entails an assessment of the response bias as a possible selection bias (Greenstein, 2006; Moule et al., 2017; Polit & Beck, 2017). Not everyone wants to participate in research. The choice of population in this study may have resulted in a bias of the sample, because it proved to be difficult to recruit families with elderly cancer patients in the palliative phase. I have previously discussed the choice of applying a wide definition of family, and the fact that the study recruited only families connected by blood or marriage (see section 8.2.3). This leads to a clear selection bias, since the results cannot automatically be transferred to families with other types of connections. To assess whether a sample is representative, it is common to collect data on the diagnosis, age and gender of the people who declined to participate. In order to compare the families in this study with the families who declined, we would need data on e.g. family connections, living arrangements and the geographical distance between the family members. That would be demanding. Our sample exclusively consists of families with elderly cancer patients ≥ 65 years. There is an equal proportion of female and male

patients. More of the male patients than the female patients were married, i.e. far more female patients lived alone. This shows that the sample is heterogeneous. The fact that we cannot say anything about representativeness and the sample's heterogeneity is a weakness in the study. We must therefore be cautious about generalising findings to the total population of family members of elderly cancer patients in the palliative phase.

The participants in this study had to accept participation in both the family group interview and the questionnaire survey, which may have had both a positive and a negative effect on the number of people who wanted to participate. As discussed earlier (see section 6.2.2), recruiting people to participate in studies on palliative care and for group interviews can be challenging. As regards questionnaire surveys, some people have difficulties reading and understanding questions and filling in questionnaires, and therefore refrain from participating in research (Greenstein, 2006; Polit & Beck, 2017). As shown in the study, elderly cancer patients in the palliative phase are often frail with comorbidity, their symptom burden may be extensive and they may not have much energy to participate in research. The spouses of elderly patients are also frequently frail, and spouses, adult children and children-in-law may have extensive caregiving responsibilities and not have the energy to participate in research. These are biases in the sample that are difficult to find a way around, since participation in research must be voluntary (Ruyter et al., 2014).

Another factor that could influence the number of participants and result in sampling bias is the quality of family relationships. Families with strained and conflicted relationships probably did not want to participate in the study, particularly since the data collection method was family group interviews and the topic for discussion was family relationships. We can therefore assume that the families in this study perceived their family relationships as positive. This can furthermore have affected the family members' score on both the CRA and the SPS, as discussed above (see sections 4.2 and 4.4). Some studies have mapped the

connections between caregiver reactions and family functions, the quality of relationships and/or marriage satisfaction (Braun et al., 2007; Francis, Worthington, Kypriotakis, & Rose, 2010). Questionnaires that map the quality of family relationships and that have been psychometrically tested for the target group, could have provided valuable additional information to this study. We did not however want to burden the participants with too many questions.

The external validity of the sample is about whether the findings can be generalised to other family members with caregiver responsibilities, and to other settings and over time (Moule et al., 2017; Polit & Beck, 2017). In such case, the sample must be representative of the whole population (Moule et al., 2017). In the above, we discussed factors that may have influenced the representativeness of our sample. The demographic characteristics of the sample are described in detail in section 6.2 and discussed in sections 8.2.2 and 8.2.3. We must therefore interpret with caution any transferring of the findings to families in other settings and over time.

When using questionnaires as a *data collection method*, there is a risk that the participants give incorrect answers because they do not understand the questions or the way they should answer them (Greenstein, 2006; Polit & Beck, 2017). In this study, all the questionnaires were filled in while the PhD candidate was still present. This can be considered a strength of the study, since the PhD candidate was able to clarify ambiguities and ensure that all questions were answered (Greenstein, 2006; Moule et al., 2017; Polit & Beck, 2017). The PhD candidate had to help two spouses read and fill in the questionnaires, which shows earlier findings that filling in questionnaires can be difficult for older people. The fact that the PhD candidate was present and helped two spouses fill in the questionnaire could also lead to a bias. We know that some participants might give incorrect answers on purpose, either because they want to be appear more socially acceptable or because they think that these are the

answers the researcher wants. A researcher's presence can also make the participants less certain about their anonymity (Greenstein, 2006; Moule et al., 2017). Regardless, the two participants who were given help to fill in the questionnaires were both grateful for the help. In addition, the questionnaires were filled in after the family group interviews, during which the PhD candidate was hopefully able to establish a secure relationship with the participants by showing interest, respect and sensitivity.

A research study must be *statistically reliable* for it to be possible to generalise the results (Moule et al., 2017). Including families with different numbers of participants in the children/children-in-law group introduces a bias in relation to representation, since the families will have different weighting in the analysis (S. P. Clarke, 1995; Polit & Beck, 2017). Another weakness of the study is its small sample size, which results in low statistical power (Polit & Beck, 2017). Furthermore, we only managed to recruit a sufficient number of daughters (n=26) and could therefore not compare the daughters, sons and children-in-law groups. Instead, we chose the children/children-in-law group (n=44), which we compared to spouses (n=14). Other studies also show that it is difficult to recruit participants for studies in palliative care (Goldstein et al., 2004; Jordhøy et al., 1999; Park et al., 2012). A small sample increases the risk of type II errors. Type II errors mean that only relatively big clinically significant differences will be significant when comparing the groups (Sloan, 2003). Non-significant findings and the discussion based on these findings must therefore be interpreted with caution, because we may have overlooked a statistical difference between the groups. Because we could not find other studies that compare caregiver reactions and social support among different groups of family members of cancer patients in the palliative phase, we found it important to analyse both the dimensions and items, although it entailed many tests. The use of parametric t-tests on a small sample can also be a weakness in the study; we discuss the rationale behind carrying out parametric t-tests in section 6.4.4.

8.3 Implications for practice

The health care service's goal when offering palliative care is to reduce suffering and promote the quality of life of both patients and their family. Findings from this study reveal that it is important for elderly, home-dwelling cancer patients in the palliative phase and their immediate family members to have a positive final time together. At the same time, the families experience relational challenges relating to the illness and their encounters with the health care service, which make it difficult to have a positive final time. Helping the families to have a positive final time together will contribute to the patients being able to live at home for as long as possible and to the family members being able to cope with their caregiving responsibilities while also taking care their own health. We consider the following to achieve this:

- Health care personnel who work with cancer patients in the palliative phase are encouraged to develop family systems competence and focus their work on the family.
- Health care personnel is encouraged to offer help and support to families who need and want it, to handle relational problems resulting from challenges caused by the illness. Such help and support should include information about the relational challenges the cancer can cause, which the family should be aware of in order to prevent the situation from becoming extra stressful. The families should also get help to understand that family interactions and relationships are reciprocal, to talk to each other about relational challenges and how to handle and solve them.
- The health care service should establish systems (e.g. including measures in pathway descriptions) that ensure that the family is involved in the health care service's cancer follow-up care of frail elderly patients. The systems should map the individual family's preferences for involvement so that adaptations to the family's needs can be made. Such mapping should include investigating the help and support available to the

individual patient when he/she is at home. Furthermore, each family's preferences in relation to the exchange of information with the health care service about the patient's health situation and the family's need for family conversations should be mapped and followed up.

8.4 Future research

This study shows that there is a need for more in-depth knowledge about the relational challenges families experience as a result of challenges relating to illness, and about how families work together to solve these challenges. It also seems important to design studies that can test various measures aimed at helping and supporting families with regard to relational challenges. Such measures can focus on teaching and on guidance and support. Studies should be carried out both in the context of cancer in the palliative phase and in relation to other life-threatening and/or chronic diseases such as cardiovascular disease and neurological disorders. Such studies should be designed for patients of all ages and in different stages of life, families with different structures and in different cultures.

Studies should also be conducted that test various systems for family involvement in the health care service's follow-up care of patients. Both qualitative and quantitative studies will be useful in this connection to identify the experiences and needs of patients, family members, family units and health care personnel.

As regards the specific findings of this study, it seems important to further investigate how families can talk to each other about and divide responsibilities and tasks relating to cancer in the palliative phase. In this context, family group interviews can be a useful data collection method, since they seem to provide important data on interactions and relationships.

Family group interviews as a data collection method are recommended to be used in further studies in order to evaluate the strengths and weaknesses of the method in different contexts,

and to evaluate when family group interviews are and are not suitable for identifying individual and family experiences. Combining family group interviews with individual interviews of patients and family members can be one way of further testing family group interviews as a data collection method.

There is a need for further research to clarify the connection between social support and family members' caregiver reactions in relation to cancer in the palliative phase. Among other things, studies that compare caregiver reactions and social support in relation to different family structures and in family members with different relational connections to the patient seem important. Longitudinal studies designed able to suggest causal connections are also relevant. Longitudinal studies report divergent findings in relation to changes in caregiver reactions over time. Some studies find that the reactions are stable (Germain et al., 2017; B. Given et al., 2004; Lee et al., 2013), others that the caregiver reactions increases if the patient's health deteriorates (Grant et al., 2013; Grunfeld et al., 2004). This topic could therefore benefit from larger, longitudinal studies.

9 CONCLUSIONS

Cancer in the palliative phase in an elderly home-dwelling family member is a family concern. The study shows that families can experience relational challenges resulting from challenges caused by the illness, that family members with different relational connections to the patient can experience caregiver responsibilities and access to social support differently, and that the health care service were not always adapted to the families' need for help and support. Together, all these factors can challenge the family unit and the family relationships. Relational challenges can make the patients' and family members' situation more difficult and challenge the desire to have a positive final time together. In order for the patients to be able

to stay at home and for family members to handle the caregiver responsibilities in the home without becoming exhausted or ill, it seems important for the health care service to meet the families as a system. Families may need help and support to handle relational challenges. For the health care service, mapping each family's situation will help to make its services more targeted and adapted to the whole family's needs.

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LIST OF PAPERS

Paper 1: Fjose, M., Eilertsen, G., Kirkevold, M., Grov, EK. (2016) *A valuable but demanding time. Family life during advanced cancer in an elderly family member.* Advances in Nursing Science, Vol 39 Issue 4, pp 358-373.

Paper 2: Fjose, M., Eilertsen, G., Kirkevold, M., Grov, EK. (submitted) *Caregiver reactions and social provisions among family members caring for home-dwelling patients with cancer in the palliative phase: A cross-sectional study.*

Paper 3: Fjose, M., Eilertsen, G., Kirkevold, M., Grov, EK. (2018) *'Non-palliative care' – A qualitative study of older cancer patients' and their family members' experiences with the health care system.* BMC Health Services Research 18:745

Caregiver reactions and social provisions among family members caring for home-dwelling patients with cancer in the palliative phase: A cross-sectional study

Abstract

Background: Studies focusing on the impact of caregiving for older adult home-dwelling patients with cancer in the palliative phase, particularly the burdens on different family caregiver groups, are limited. The objective of this study was to assess and compare caregiver reactions and social provisions among different family caregiver groups in Norway.

Methods: The sample consisted of 58 family members caring for 26 home-dwelling older adult patients with advanced cancer. The Caregiver Reaction Assessment and Social Provisions Scale were used to assess the caregiver reactions and social support, respectively. The analyses were performed using descriptive statistics.

Results: Significant differences were revealed between the family caregiver groups in the following three dimensions of the Caregiver Reaction Assessment: *impact on schedule*, *lack of family support* and *impact on health*. Significant differences were revealed between the family caregiver groups in the following two dimensions of the Social Provisions Scale: *nurturance* and *attachment*.

Conclusions: In our study, children and children-in-law caring for widowed patients and spouses were the most vulnerable family caregivers. We recommend assessing the caregiver situation of all available family members caring for older adult patients with advanced cancer to identify the most vulnerable caregivers.

Keywords: caregiver reaction, social provisions, family relationship, family caregiver group, cancer, palliative phase

1. Background

Cancer can be divided into two overall phases, i.e., the curative phase and palliative phase. The palliative phase typically “starts with the recognition of incurable disease, and continues until the patient dies” (1). Three-quarters of all patients with cancer in the palliative phase are 65 years old or older (2, 3). The increased number of older adults, longer survival, health care policies that emphasize community care (4, 5) and the patients’ wishes to remain at home even during the palliative phase (6, 7) place heavy demands on family caregivers. Due to comorbidities, these demands can be physical, social, emotional and financial (8, 9).

The patient’s situation and ability to remain at home are determined by access to support and care, family caregivers’ ability to provide such support and care (10), and family caregivers’ experience with caregiving (11). Older adult patients may have lost their spouses, or their spouses may be frail and unable to provide care. Therefore, children and/or other close family members are given more caregiving responsibility (8). Caregiving may physically, psychologically, socially and existentially affect the caregivers (5, 11). Caregiving can have positive effects, such as the promotion of maturation and growth (5). However, caregiving is also associated with negative effects, such as stress, anxiety, depression, fatigue, family conflict and health problems (12, 13). Given et al. (2004, s.1106) described the negative caregiver reaction as follows: “a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to the caregivers’ personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill”.

Several measures have been developed to assess the reactions of caregivers caring for a sick family member (11, 14, 15). Studies have been performed in different contexts and have focused on the frail elderly, dementia care, and mental illness (15-17). In the context of advanced cancer, both cross-sectional and longitudinal studies have been performed, and most studies have assessed the patient and caregiver characteristics and the effects of these characteristics on caregiver reactions (18-23).

Family members with different relationships to a patient, e.g., spouses, children and children-in-law, may experience caregiving differently (8, 24). In addition, the primary caregiver may have a different experience with caregiving than family members who support the primary caregiver or family caregivers who have equal caregiving responsibility (8). However, only a few studies have assessed and compared caregiver reactions across different family caregiver groups in the context of cancer (8, 25-28). According to several literature

reviews, studies investigating cancer caregiving have mostly involved one family member per patient, i.e., the person defined as the primary caregiver. Typically, this person is the patient's spouse or daughter. However, sons, other family members and friends have also been investigated (10, 12, 29). Only one study performed by Lowenstein and Gilbar (2000) compared the caregiver reactions of a patient's spouse and children. The spouse exhibited the most severe caregiver reactions. However, the patients were newly diagnosed with cancer and in the initial stage of the illness. Lund, Ross, Petersen and Groenvold (2014) compared the experiences of different family caregiver groups (e.g., spouses, parents and children) with caregiving tasks and the consequences of their role and function. The authors recruited more than one caregiver for approximately one third of the 415 cancer patients at various disease stages and found that the spouses experienced the highest workload. Other studies comparing different family caregiver groups recruited one family caregiver per patient and found that adult children exhibited the most severe caregiver reactions (25-27). Kim et al. (2007) recruited caregivers of cancer survivors and found that daughters experienced the most stress as a result of caregiving, followed by spouses, and sons experienced the lowest level of caregiver stress. Except for the study conducted by Lowenstein and Gilbar (2000), we could not identify studies comparing the caregiver reactions of different family caregiver groups caring for older adult home-dwelling patients with cancer.

Social support in different contexts, such as cancer and heart disease, positively affects illness and health (30-32). Social support is conceptualized as "the functions that are provided by social relationships" (33). According to Wright and Leahey (2013), family is an essential source of support because family members protect, nurture and socialize with each other. According to the theoretical model proposed by Weiss (1974), different relationships meet different inter-relational needs. The following six dimensions of social provisions were defined: attachment, social integration, reassurance of worth, opportunity for nurturance, guidance and reliable alliance. These dimensions describe how different relationships provide different types of social support (34). The social provisions of attachment are mainly provided by the spouse, other family members and close friends, and social integration is mainly provided by friends and spouses. Weiss (1974) suggested that all six dimensions are needed, but the relative importance of the dimensions may differ depending on the personality, beliefs, situations and life stages of the individual (34).

Several studies consider social support a buffering factor in providing care for a family member with advanced cancer and report that satisfactory social support diminishes caregiver burden (22, 23, 26, 35-38). In contrast, one study conducted in Norway (39) found that high levels of social provisions did not decrease

caregiver burden. However, the above-mentioned studies did not compare the caregiver burden among different family caregiver groups.

Knowledge regarding how family members with different patient relationships, such as spouses and children/children-in-law, and children/children-in-law related to patients with or without an available spouse experience the caregiver situation and social provisions is lacking. Thus, studies investigating these experiences in the context of home-dwelling patients with cancer in the palliative phase are warranted (5, 11, 16). Therefore, the aim of this study is to assess and compare caregiver reactions and social provisions among different family caregiver groups caring for home-dwelling older adult cancer patients during the palliative phase.

2. Methods

2.1 Study design and sample

This cross-sectional study was performed between February 2012 and November 2013. Nurses working in hospital wards, out-patient units and district services in Western and Eastern Norway invited patients and potential family members to participate in the study. We used the following well-known definition of “family”: whoever the patient claims is a member of his/her family (40). Non-ethnic Nordic families are rare in Western Norway. Therefore, to ensure homogeneity, eligible families included ethnic Nordic families with one family member aged ≥ 65 years who was diagnosed with cancer in the palliative phase and cared for at home. Co-morbidities were not included in the exclusion criteria. The patients who were willing to participate decided in collaboration with their families, which family members over the age of 18 would participate in the study.

2.2 Demographics and measures

Data regarding the patients’ and family members’ sociodemographic characteristics were collected. The patient characteristics included age, gender, cancer type and palliative phase, and the family members’ characteristics included age, gender, geographic distance to the patient, education level, employment status, marital status and relationship to the patient.

2.2.1 The Caregiver Reaction Assessment

One of the two outcome variables in this analysis was family members’ caregiver reactions, which was measured using the Caregiver Reaction Assessment developed by Given et al. in 1992 (41). This questionnaire consists of 24 items and assesses the following 5 dimensions: *self-esteem* (7 items), *lack of family support* (5

items), *financial impact* (3 items), *impact on daily schedule* (5 items) and *impact on health* (4 items). The family members responded on a 5-point Likert scale with 1 indicating *strongly disagree*, 2 indicating *disagree*, 3 indicating *neither agree nor disagree*, 4 indicating *agree*, and 5 indicating *strongly agree*. The composite score of each dimension is the mean rating of the items in each dimension (range from 1.0 to 5.0). The subscale of family member's *self-esteem* measures the positive experiences of caregiving, and a lower score indicates greater burden. The other four subscales assess the negative experiences of caregiving, and higher scores indicate higher levels of burden. The Caregiver Reaction Assessment has been widely used in studies investigating advanced cancer caregiving and has been psychometrically tested and validated (11, 14-16), including in Norway (19, 39). The psychometric properties have been reported to be satisfactory using the same dimensions as the original version.

2.2.2 The Social Provisions Scale

To examine the availability of social provisions, the revised Social Provisions Scale (42) was used to measure the second outcome variable. This scale originally consisted of 24 items and six dimensions (34). Two dimensions (i.e., reliable alliance and guidance) were highly correlated with the other dimensions; therefore, these dimensions have been omitted from the revised Social Provisions Scale (42). The revised Social Provisions Scale consists of 16 items, including 4 items covering each of the following four dimensions: *attachment*, *social integration*, *opportunity for nurturance* and *reassurance of worth*. The family members responded on a four-point Likert scale with the following response options: *strongly agree*=4, *agree*=3, *disagree*=2, and *strongly disagree*=1. Higher scores indicate higher levels of social provision. The Social Provisions Scale has been used in studies investigating cancer caregiving and gerontology (30, 32, 39, 43). Psychometric testing of the Norwegian version of the Social Provisions Scale using confirmatory factor analysis sustains the factor structure suggested in the revised 16-item Social Provisions Scale (44).

2.3 Procedures

Because this topic is sensitive and complex (45) and recruiting large family units may be difficult (46), we attempted to recruit four family members per patient. The first author was present in the patients' homes during data collection. The family caregivers were instructed about how to interpret the different questions and informed that we were interested in their experiences with each item. If the participants required assistance due to difficulties in understanding the questions, the researcher (the first author) provided clarification or helped the participants complete the questionnaires. A few spouses needed assistance.

2.4 Statistical analyses

The data were analysed using SPSS version 24 (SPSS Inc., Chicago, IL). To determine the reactions of the family caregivers to caregiving and perceived social provisions, we first examined the data, particularly the skewness and kurtosis statistics, which had low values indicative of normal distributions. The mean and median values were mostly similar. However, we performed both non-parametric (Mann-Whitney U-tests) and parametric (t-tests) tests to evaluate each item and dimension of the assessment tools. In the group comparisons, all p-values were consistent, except for item 11 on the Caregiver Reaction Assessment in the comparison of the spouses and children (0.04 (t-test) versus 0.08 (U-test)). Because we sought to compare our results with other studies reporting mean values and SDs of the Caregiver Reaction Assessment, we therefore show mean and SD values for each item, and the corresponding p-values to present the possible differences between the groups in this study. Furthermore, a Spearman's rho correlation analysis of the dimensions on the Caregiver Reaction Assessment and Social Provisions Scale was performed. To compare the caregiver reactions and social provisions of family members with different relationships to the patients, the following caregiver groups were constructed: spouses and children/children-in-law. Due to the low number of participants, we were unable to construct separate daughter, son and children-in-law groups. To explore whether the availability of a patient's spouse affected the children and children-in-law caregiver reactions and social provisions, the following two groups were constructed: children/children-in-law of married patients and children/children-in-law of widowed patients. The level of significance was set at $p < .05$ and all tests were two-sided.

3. Results

3.1 Sample

In total, 75 information letters were distributed to eligible families, and 33 families consented to participate. Seven families withdrew before the day of the interview because of the patient's impaired health status; thus, 26 families participated in this study.

The sample consisted of 58 family members caring for 26 older adult patients with cancer in a palliative phase with a mean of 3 (range 1-4, median 3) family members per patient. Thirteen patients were women, and 13 patients were men. Fourteen spouses, two children and one son-in-law lived in the same household as the patient. Among the family members who did not reside in the same household as the patient, the mean distance to the

patient's home was 8.26 miles (range 0-68.3 miles, median 2.5 miles). Only one of the employed family members was a spouse. The patients' cancer sites included lung (7), prostate (6), colon (6) and other (7). Most (69%) patients displayed comorbidity. Fifteen patients were diagnosed within two years of the interview, and 13 patients had metastatic cancer at the time of diagnosis. Of the spouses, 30% had multiple diagnoses. Tables 1 and 2 display the demographic characteristics of the families.

--Insert Tables 1 and 2 about here--

3.2 Differences in the dimensions and single items of the Caregiver Reaction Assessment between family caregiver groups

Significant differences were revealed between the caregiver groups in the following three (of five) Caregiver Reaction Assessment dimensions: *impact on schedule*, *lack of family support* and *impact on health* (see Figures 1-4). To illustrate the differences in the single items of the Caregiver Reaction Assessment, the means, SD and *p*-values of all caregiver groups studied are presented in Tables 3 and 4.

3.2.1 Impact on schedule

The spouses exhibited significantly higher scores on the disrupted schedule dimension than the children/children-in-law, $p=.013$ and children/children-in-law of married patients, $p=.009$. The results of the schedule dimension are presented as single items. The spouses exhibited significantly higher scores on item 4 ("my activities are centred on care") and item 14 ("eliminate from schedule") than the children/children-in-law and children/children-in-law of married patients. The spouses also scored significantly higher on item 18 ("interruptions") than the children/children-in-law of married patients.

3.2.2 Lack of family support

Regarding the dimension of *lack of family support*, the children/children-in-law reported significantly greater burden than the spouses, $p=.010$. In addition, the children/children-in-law of widowed patients reported significantly higher levels of burden than the spouses, $p=.004$. Regarding the single items, the children/children-in-law scored significantly higher than the spouses on item 2 ("others dumping care on me") and item 22 ("family left me alone"), providing insight into the detailed aspects of the *lack of family support* dimension. The children/children-in-law of widowed patients exhibited significantly higher scores than the spouses on items 2

and 16 (“feel abandoned”), and higher scores than both the spouses and children/children-in-law of married patients on item 22.

3.2.3 Impact on health

The children/children-in-law of widowed patients exhibited significantly higher scores on the *impact on health* dimension than the children/children-in-law of married patients, $p=.040$. The children/children-in-law of widowed patients exhibited significantly higher scores than the children/children-in-law of married patients on item 5 (“tired all the time”) and item 10 (“health has gotten worse”) and higher scores than the spouses on item 19 (“healthy enough to care”). Furthermore, the spouses scored significantly higher than the children/children-in-law of married patients on items 5 and 10.

--Insert Figures 1-4 about here--

--Insert Tables 3 and 4 about here--

3.3 Differences in the dimensions and single items of the Social Provisions Scale between the family caregiver groups

Significant differences were revealed in the following two (of four) Social Provisions Scale dimensions: *nurturance* and *attachment*. The spouse scores on the *nurturance* dimension were significantly higher than those of the children/children-in-law of widowed patients, $p=.041$. Regarding the single items, the only significant difference was observed in item 9 (“There is no one who really relies on me for their well-being”), and the children/children-in-law of married patients scored higher on this item than the children/children-in-law of widowed patients. The children/children-in-law of married patients exhibited significantly higher scores on the *attachment* dimension than the children/children-in-law of widowed patients, $p=.032$. Regarding the single items, the children/children-in-law of married patients exhibited significantly higher scores than the children/children-in-law of widowed patients on item 11 (“I have close relationships that provide me with a sense of emotional security and well-being”).

3.4 Relationship among the Caregiver Reaction Assessment and Social Provisions Scale dimensions

According to a bivariate correlation analysis, the dimensions in the Caregiver Reaction Assessment and Social Provisions Scale were weakly correlated. The highest negative correlation coefficient, Spearman’s $\rho=-$

0.236, $p=.05$, was found between the *lack of family support* dimension of the Caregiver Reaction Assessment and the *attachment* dimension of the Social Provisions Scale. While this finding may have been random, the relationship could be explained by a conceptual overlap between these two dimensions.

4. Discussion

In this study, we assessed and compared caregiver reactions and social provisions between different family caregiver groups caring for older adult patients with cancer in the palliative phase. The main findings include significant differences between the family caregiver groups on the following three (of five) Caregiver Reaction Assessment dimensions: *impact on schedule*, *lack of family support* and *impact on health*. Furthermore, significant differences were observed between the family caregiver groups on the following two (of four) Social Provisions Scale dimensions: *nurturance* and *attachment*.

4.1 Spouses constitute the family caregiver group with the most interrupted schedule

In the present study, the spouses reported their schedule was interrupted due to their caregiver role more often than the children/children-in-law and children/children-in-law of married patients. To the best of our knowledge, the only study using the Caregiver Reaction Assessment to compare caregiver reactions among different family caregiver groups caring for cancer patients during the palliative phase was conducted by Given et al. (2004). Their findings revealed that children/children-in-law exhibited higher scores on the interrupted schedule dimension than spouses. A comparison of the mean scores on these dimensions identified a significant difference in *impact on schedule* between the spouses in Given et al.'s (2004) study and the spouses in the present study, $p=0.013$ (dimension mean scores of 2.84 (SD 0.67) and 3.04 (SD 1.02) respectively), and the spouses in this study reported significantly higher levels of burden. This difference could be explained by the age differences in the spouses because 73% of the caregivers in Given et al.'s study were older than 55 years, while the mean age of the spouses in this study was 73.3 years. Thus, older age may be associated with health problems that could limit resources (47). Furthermore, Given et al. (2004) recruited one family caregiver per patient. If the children/children-in-law in Given et al.'s study cared for widowed patients, this group could be comparable to our children/children-in-law of widowed patients group. However, no significant differences were observed in the interrupted schedule dimension between our spouses and children/children-in-law of widowed patient group.

Our finding that spouses experienced a greater *impact on schedule* than children/children-in-law of married patients may be comparable to Lowenstein and Gilbar's (2000) findings because their children group shared caregiving responsibilities with the patient's spouse. Lowenstein and Gilbar (2000) found that spouses and children reported equal role strain scores. Role strain reflects "the level of change in various aspects of the caregiver's life, such as having insufficient time for him/herself" (8). However, because Lowenstein and Gilbar (2000) used the Caregiver Burden Scale and the patients were in the initial stage of the illness, performing comparisons is difficult. In Lowenstein and Gilbar's (2000) study, the mean age of the spouses was 70 years, which is comparable to the age of the spouses in our study; thus cultural differences could explain the differences between the Norwegian and Israeli spouses' experiences with the caregiver situation.

The current study is the only study in the context of cancer to compare different family caregiver groups and report that spouses experience the greatest impact on their schedule. Our results could be explained in terms of cultural diversity. Lowenstein and Gilbar performed their study in Israel, Given et al. (2004) performed their study in the USA, and our study was performed in Norway. In Norway, spouses, children and children-in-law are not legally obligated to care for family members. In particular, spouses might consider their role as caregivers a duty, but this view may differ from that of spouses in other countries. Spouses may feel more obligated than children and children-in-law due to several reasons, such as normative expectations of the marital bond suggesting that spouses are primary caregivers, spouses who live with the patient might tend to become more involved in caregiving tasks, and spouses perform additional tasks that were previously performed by the patient (8). Furthermore, spouses are reluctant to leave the patient alone in case of an emergency (48) and patients and spouses avoid bothering their children (4, 49, 50). Notably, the highest significant values were observed in the comparison between the spouses and children/children-in-law of married patients. We hypothesize that this result indicates that an available spouse lessens the caregiver burden of children and children-in-law.

4.2 Children and children-in-law lacking family support

In the present study, the children/children-in-law and children/children-in-law of widowed patients reported a greater *lack of family support* than the spouses. This finding is consistent with Given et al.'s (2004) study, in which the children/children-in-law reported higher levels of abandonment than the spouses. As previously mentioned, the particular group of children/children-in-law in Given et al.'s study could be comparable to our group of children/children-in-law of widowed patients. Notably, significant differences were

observed in the comparison of the children/children-in-law of widowed patients and the spouses, indicating that children and children-in-law caring for a patient with a spouse perceive a lesser degree of lack of family support.

Children/children-in-law and children/children-in-law of widowed patients may lack more family support than spouses for several reasons. According to traditional and cultural family rules, spouses are expected to care for a sick spouse (47). However, as previously mentioned, patients and spouses often protect children from the caregiver burden (8, 24, 48, 50) and, therefore, likely do not expect children and children-in-law to support them in caregiving. Children and children-in-law are not expected to provide much caregiving (26); have multiple role obligations, such as home, children and work, in addition to caregiving ((24, 26, 51); and may therefore be in need of help and expect family members to share the caregiving responsibility (51).

4.3 Caregiver health: are children/children-in-law of widowed patients the most vulnerable group?

The group of children/children-in-law of widowed patients reported more health problems than the children/children-in-law of married patients. To the best of our knowledge, no other studies have reported comparable findings within the context of cancer. The children/children-in-law of widowed patients could have had more health problems. In this case, older age might be an explanation, but no differences was observed in age between the groups, $p=.06$. Another explanation might be that because the children/children-in-law of widowed patients had to spend more time checking on the patient in the absence of a spouse, these participants felt more exhausted. In patients with a spouse, the partner is often present to check on the patient and call for help if needed.

Interestingly, although several of the elderly spouses in our study reported the presence of multiple diagnoses, they did not report a greater *impact on health* than any other group. However, the spouses scored significantly higher than the children/children-in-law of married patients on two single items (“tired all the time” and “health has gotten worse”). Thus, the spouses in our study likely expected worsened health due to old age or only related their health problems to their older age and not to caregiving. In several Asian studies, the spouses reported more health problems than non-specific groups of caregivers (22, 52). Additionally, older caregivers tend to report more health problems than young caregivers (4, 35). However, these studies did not compare specific family caregiver groups and only recruited primary caregivers; thus, comparing these studies with our study is challenging.

4.4 Children and children-in-law of widowed patients perceive lack of social support

To the best of our knowledge, no published studies have investigated social support among family caregiver groups caring for patients with cancer in the palliative phase, using the Social Provisions Scale. Thus, comparing our findings to other studies is difficult.

The group of children/children-in-law of widowed patients in our study reported significantly lower levels of *attachment* than children/children-in-law of married patients. According to Weiss (1976), *attachment* provides security and safety and is mainly provided by a spouse, other family members and close friends. Comparing the two groups, more children in the children/children-in-law of widowed patients group lived with a spouse, indicating that the absence of a spouse had no impact on their report on *attachment*. However, the presence of a spouse does not automatically imply available support. The children/children-in-law of widowed patients group ($n=21$) consisted of 6 sons, 6 children-in-law and 9 daughters, and the children/children-in-law of married patients ($n=23$) consisted of 17 daughters, 5 sons and 1 child-in-law. The children/children-in-law of widowed patients had fewer family members and friends to provide security and safety. Because the family caregiver group of children/children-in-law of married patients mostly consisted of daughters (17 of 23), the children/children-in-law of married patients group may have scored higher on the attachment dimension than the children/children-in-law of widowed patients group due to the following reasons: women tend to seek and receive more social support, which is consistent with other studies (53), and women might have a social network that provides safety and security. Sons tend to primarily rely on one person, i.e., their spouse, for social support (32). Furthermore, the children/children-in-law of widowed patients may have reported lower levels of *attachment* due to the forthcoming loss of their last parent. Parents are possible sources of attachment support who they have to support and protect in this situation.

The spouses exhibited significantly higher scores on the *nurturance* dimension than the children/children-in-law of widowed patients. *Nurturance* comprises the participants' perception of their responsibility for another person's well-being (34). The spouses' high score may reflect their caring responsibility for their spouse. According to Weiss (1974), the opportunity to nurture another human being has a positive impact on self-esteem. Interestingly, in this study, the spouses reported significantly higher scores than all other family caregiver groups on the "privilege to care" item of the Caregiver Reaction Assessment self-esteem dimension. Spouses are reluctant to involve others in the patient's care (4) likely because they find it rewarding to support their spouse, which positively affects their self-esteem.

4.5 Study strengths and limitations

Given the lack of studies differentiating specific family relationships to the patient, one strength of this study is the assessment performed using standardized instruments and analyses comparing different caregiver groups. Analysing each item of the two instruments resulted in many tests. However, this study is explorative, and similar studies have never been performed; thus, analyzing the items and dimensions in each caregiver group is valuable. Further studies should include more respondents and larger groups to enable multiple testing.

The correlation among the dimensions of the Caregiver Reaction Assessment and Social Provisions Scale were weak, indicating that the two instruments cover different main concepts, i.e., caregiver reactions and social provisions, respectively. The researcher's availability while the participants were completing the questionnaire ensured that all items were completed. The weakness of this study is the number of respondents. We attempted to recruit four family members per patient. This delimitation may have resulted in recruiting fewer participants, more participants would have likely been included if we performed open recruitment and included everyone in the family who wanted to participate. To ensure robust groups in the statistical analyses, we were unable to separate the sons, daughters and children-in-law into specific groups. Including families with different numbers of participants into the group "children/children-in-law" introduced bias in representability because the families had unequal weight in the analyses. Recruitment for studies involving patients with cancer in the palliative phase has been reported to be challenging (22, 26, 54), which was the case in this study. Although we used a wide definition of family in the recruitment process, the sample consisted of only biological and intermarried family members. This sample may exist because the nurses who recruited the families asked only biological families to participate. In addition, most families are from rural Norway, where biological families are the most common type of families, representing the homogeneity of the family structure in Norway.

4.6 Practical implications and future studies

Providing care to an elderly home-dwelling family member with advanced cancer is a demanding task (8, 10, 15, 25) that may result in burden on all close family members. In this study, the nature and severity of the burden varied across family members with different relationships to the patient (e.g., spouses and children/children-in-law) and between children/children-in-law of married and widowed patients. Thus, the family members' relationship to the patient and family structure may inform which interventions are beneficial.

To help family members manage caregiving and target interventions, health care professionals should assess the impact of caregiving on all available family members.

Because the study of the burden of caregiving among different family caregiver groups is in its infancy, further studies are needed to clarify the nature and severity of the stress experienced and how this stress varies as a function of the family structure and the caregiver's relationship to the patient. Qualitative studies are needed to obtain deeper insight into how different family caregiver groups experience the caregiving situation, how different family members organize their caregiving and what factors affects their attitudes and actions.

5. Conclusions

Caregiving affects all close family members of home-dwelling older adult patients with advanced cancer, and in this study, specific family caregiver groups expressed this burden differently. The elderly spouses reported the greatest *impact on schedule*. The children/children-in-law and children/children-in-law of widowed patients reported the greatest *lack of family support*, and the latter group also reported the greatest *impact on health*. Therefore, children and children-in-law caring for widowed patients and spouses were the most vulnerable family caregivers in our study. This perspective on family caregivers' self-reported burden adds to the family caregiving field because our assessment and analysis included several different caregiver groups.

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Table 1. Sociodemographic characteristics of the participants

Characteristic	mean	range
Family members' age (N=84)		
Patients	78.7	(65-92)
Domestic partners	73.3	(55-84)
Sons	48.6	(33-56)
Daughters	45.9	(27-62)
Sons-in-law	63	
Daughters-in-law	44.5	(34-53)
Characteristic	n	%
Relationship of the family member to the patient (N=58)		
Wife	10	16
Husband	4	7
Son	11	18
Daughter	26	43
Son-in-law	1	2
Daughter-in-law	6	10
Adult offspring's marital status (N=37)		
Married	24	65
Unmarried	13	35
Family members' educational level (N=58)		
High school or above	31	52
Below high school	29	48
Family members' employment status (N=58)		
Employed full-time or part-time	45	75
Retired, sick leave or-un employed	15	25

Table 2. Clinical variables of the patients and their domestic partners

Patients			Domestic partners	
Cancer types		Other diseases		Other diseases
Lung	7	Cardiovascular diseases	10	4
Prostatic	6	Polymyalgia	1	
Breast	1	Hearing impairment	4	1
Colon	6	Musculoskeletal diseases	9	6
Amyloidosis	1	Mental diseases	1	
Gynaecologic	1	Cerebri diseases	4	2
Mole	2	Renal failure	1	1
Bone marrow	1	COPD, asthma	3	
CML	1	Diabetes	2	2
Myelomatosis	1	Vision impairment	1	
Unknown	1	Chron's disease	1	

Figure 1. Comparison of caregiver reaction dimensions between domestic partners and adult offspring/children-in-law

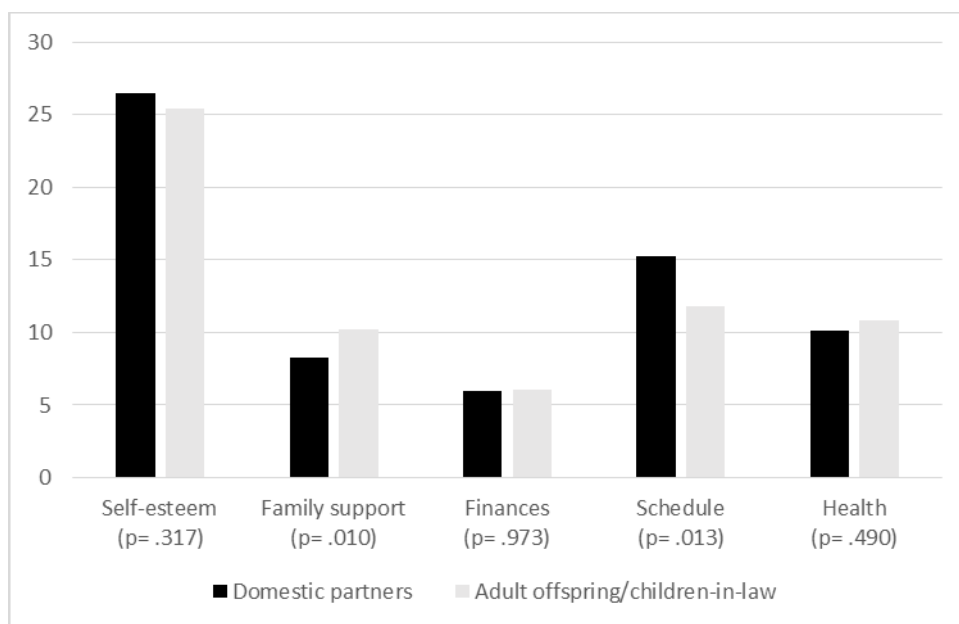


Figure 2. Comparison of caregiver reaction dimensions between adult offspring/children-in-law of married patients (AOmP) and adult offspring/children-in-law of widowed patients (AOwP)

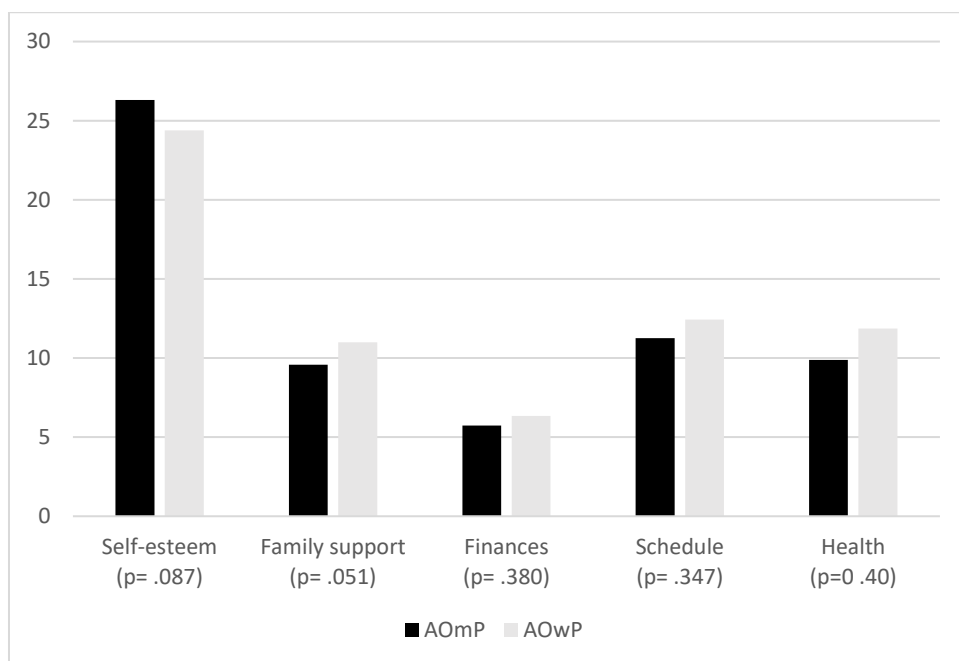


Figure 3. Comparison of caregiver reaction dimensions between domestic partners and adult offspring/children-in-law of married patients (AOmP)

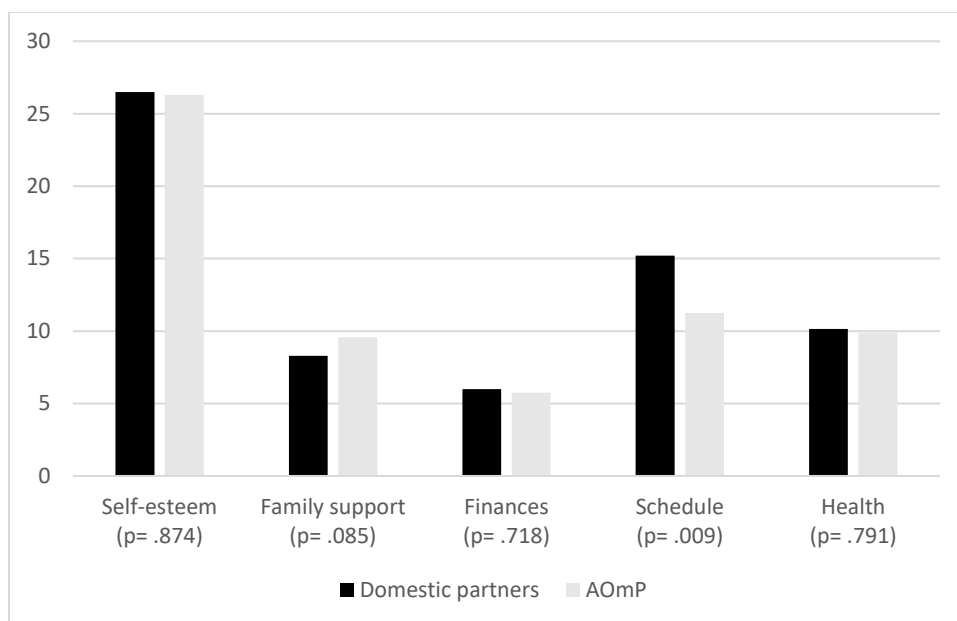


Figure 4. Comparison of caregiver reaction dimensions between domestic partners and adult offspring/children-in-law of widowed patients (AOwP)

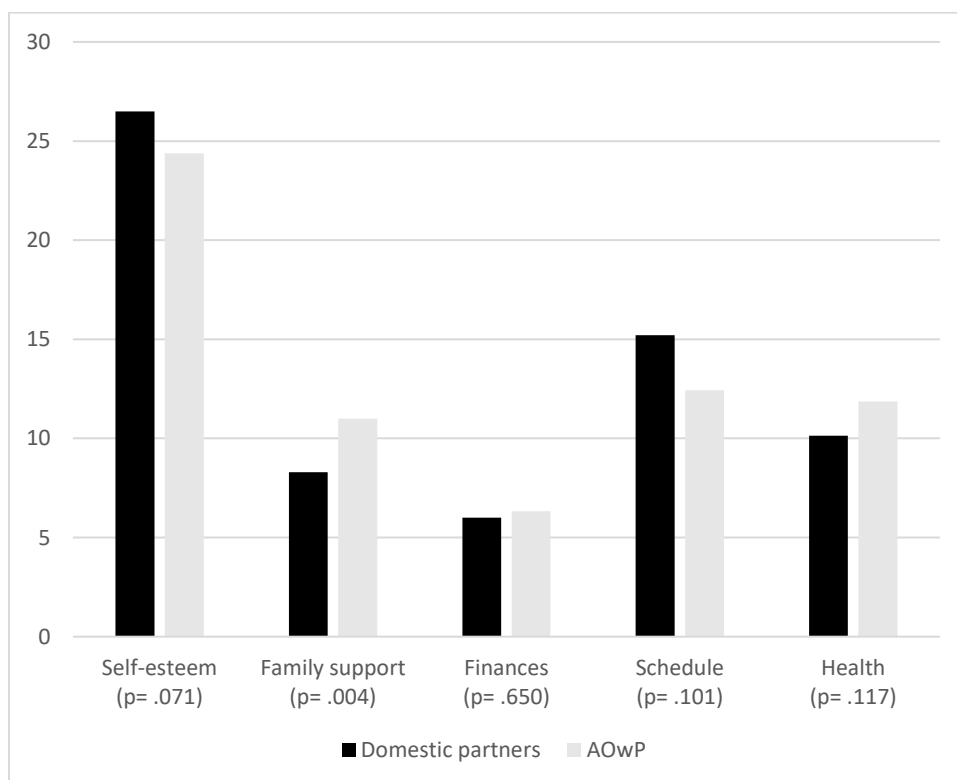


Table 3. Comparison of single items on the Caregiver Reaction Assessment between different family caregiver groups

	Domestic partners	Adult offspring/ children-in-law	
	n=14	n=44	
	mean (SD)	mean (SD)	P value
Items			
1. Privilege to care	4.79 (0.43)	4.23(0.74)	0.010
2. Others dump caring	1.21 (0.58)	1.82(0.97)	0.032
3. Finances adequate	3.29 (1.54)	2.91(1.44)	0.406
4. Activities centred on care	3.36 (1.15)	2.59(0.1.00)	0.019
5. Tired all the time	2.64 (0.84)	2.41(1.19)	0.498
6. Difficult to get help	1.50 (1.09)	1.70(0.88)	0.478
7. Resent having to care	2.29 (1.54)	2.27(1.55)	0.978
8. Stop work to care	2.29 (1.44)	2.11(0.97)	0.611
9. Want to care	4.14 (1.17)	3.98(0.95)	0.594
10. Health has gotten worse	2.21 (1.31)	1.64(0.81)	0.052
11. Visit family/friends less	3.21 (1.72)	2.30(1.29)	0.037
12. Never do enough to repay	3.29 (1.44)	3.02(1.28)	0.519
13. Family works together	3.29 (1.59)	3.45(1.13)	0.662
14. Eliminate from schedule	3.50 (1.60)	2.57(1.35)	0.036
15. Physical strength	2.50 (1.34)	3.27(1.40)	0.075
16. Feel abandoned	1.14 (0.36)	1.55(0.76)	0.062
17. Caring makes me feel good	3.86 (1.10)	3.89(0.89)	0.920
18. Interruptions	2.86 (1.10)	2.25(1.10)	0.078
19. Healthy enough to care	2.79 (1.19)	3.50(1.59)	0.128
20. Caring is important to me	4.29 (0.73)	4.09(0.77)	0.408
21. Financial strain	1.43 (0.76)	1.52(0.76)	0.688
22. Family left me alone	1.14 (0.36)	1.73(0.90)	0.022
23. Enjoy caring	3.86 (0.95)	3.91(0.80)	0.841
24. Difficult to pay	1.29 (0.61)	1.59(0.84)	0.217

Table 4. Comparisons of single items on the Caregiver Reaction Assessment between different family caregiver groups

Items	Domestic partners	AOmP*		Domestic partners	AOwP**		AOmP	AOwP	
	n=14	n= 22		n=14	n=15		n= 22	n=15	
	mean (SD)	mean (SD)	P value	mean (SD)	mean (SD)	P value	mean (SD)	mean (SD)	P value
1. Privilege to care	4.79 (0.43)	4.27 (0.70)	0.019	4.79 (0.43)	4.13 (0.83)	0.014	4.27 (0.70)	4.13 (0.83)	0.586
2. Others dump caring	1.21 (0.58)	1.59 (0.91)	0.177	1.21 (0.58)	1.93 (0.88)	0.016	1.59 (0.91)	1.93 (0.88)	0.263
3. Finances adequate	3.29 (1.54)	2.68 (1.39)	0.232	3.29 (1.54)	3.20 (1.57)	0.883	2.68 (1.39)	3.20 (1.57)	0.298
4. Activities centred on care	3.36 (1.15)	2.45 (0.96)	0.016	3.36 (1.15)	2.60 (1.18)	0.092	2.45 (0.96)	2.60 (1.18)	0.683
5. Tired all the time	2.64 (0.84)	1.91 (0.75)	0.010	2.64 (0.84)	3.07 (1.44)	0.346	1.91 (0.75)	3.07 (1.44)	0.003
6. Difficult to get help	1.50 (1.09)	1.55 (0.67)	0.878	1.50 (1.09)	1.80 (1.08)	0.464	1.55 (0.67)	1.80 (1.08)	0.382
7. Resent having to care	2.29 (1.54)	2.32 (1.73)	0.955	2.29 (1.54)	2.27 (1.49)	0.973	2.32 (1.73)	2.27 (1.49)	0.926
8. Stop work to care	2.29 (1.44)	1.91 (0.87)	0.332	2.29 (1.44)	2.27 (1.22)	0.970	1.91 (0.87)	2.27 (1.22)	0.304
9. Want to care	4.14 (1.17)	4.05 (1.00)	0.791	4.14 (1.17)	3.80 (1.01)	0.405	4.05 (1.00)	3.80 (1.01)	0.471
10. Health has gotten worse	2.21 (1.31)	1.41 (0.59)	0.017	2.21 (1.31)	1.87 (0.99)	0.426	1.41 (0.59)	1.87 (0.99)	0.087
11. Visit family/friends less	3.21 (1.72)	2.27 (1.16)	0.058	3.21 (1.72)	2.53 (1.60)	0.278	2.27 (1.16)	2.53 (1.60)	0.569
12. Never do enough to repay	3.29 (1.44)	3.45 (1.14)	0.698	3.29 (1.44)	2.80 (1.42)	0.369	3.45 (1.14)	2.80 (1.42)	0.131
13. Family works together	3.29 (1.59)	3.50 (1.26)	0.657	3.29 (1.59)	3.40 (1.18)	0.827	3.50 (1.26)	3.40 (1.18)	0.810
14. Eliminate from schedule	3.50 (1.60)	2.55 (1.37)	0.065	3.50 (1.60)	2.60 (1.55)	0.136	2.55 (1.37)	2.60 (1.55)	0.911
15. Physical strength	2.50 (1.34)	3.32 (1.39)	0.091	2.50 (1.34)	3.40 (1.50)	0.102	3.32 (1.39)	3.40 (1.50)	0.866
16. Feel abandoned	1.14 (0.36)	1.36 (0.49)	0.158	1.14 (0.36)	1.47 (0.74)	0.152	1.36 (0.49)	1.47 (0.74)	0.614
17. Caring makes me feel good	3.86 (1.10)	4.00 (1.02)	0.694	3.86 (1.10)	3.73 (0.80)	0.730	4.00 (1.02)	3.73 (0.80)	0.403
18. Interruptions	2.86 (1.10)	2.09 (0.87)	0.026	2.86 (1.10)	2.47 (1.51)	0.435	2.09 (0.87)	2.47 (1.51)	0.342
19. Healthy enough to care	2.79 (1.19)	3.36 (1.65)	0.264	2.79 (1.19)	3.80 (1.52)	0.057	3.36 (1.65)	3.80 (1.52)	0.421
20. Caring is important to me	4.29 (0.73)	4.23 (0.69)	0.809	4.29 (0.73)	3.93 (0.70)	0.196	4.23 (0.69)	3.93 (0.70)	0.213
21. Financial strain	1.43 (0.76)	1.50 (0.67)	0.769	1.43 (0.76)	1.60 (0.99)	0.605	1.50 (0.67)	1.60 (0.99)	0.715
22. Family left me alone	1.14 (0.36)	1.36 (0.58)	0.213	1.14 (0.36)	2.13 (1.13)	0.004	1.36 (0.58)	2.13 (1.13)	0.010
23. Enjoy caring	3.86 (0.95)	3.86 (0.77)	0.982	3.86 (0.95)	3.80 (0.86)	0.866	3.86 (0.77)	3.80 (0.86)	0.816
24. Difficult to pay	1.29 (0.61)	1.68 (1.00)	0.191	1.29 (0.61)	1.40 (0.63)	0.625	1.68 (1.00)	1.40 (0.63)	0.339
*AOmP: adult offspring/children-in-law of married patients									
**AOwP: adult offspring/children-in-law of widowed patients									

RESEARCH ARTICLE

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“Non-palliative care” – a qualitative study of older cancer patients’ and their family members’ experiences with the health care system

Marianne Fjose^{1*} , Grethe Eilertsen², Marit Kirkevold³ and Ellen Karine Grov⁴

Abstract

Background: Among all cancer patients in the palliative phase, $\frac{3}{4}$ have reached the age of 65. An aging population will increase the number of people afflicted with cancer, and create challenges for patients, family members and health services. Nevertheless, limited research has focused explicitly on the experiences and needs of older cancer patients in the palliative phase and their families. Therefore, the aim of this study is to explore what older home dwelling cancer patients in the palliative phase and their close family members, as individuals and as a family, experience as important and difficult when facing the health services.

Methods: We used a qualitative descriptive design. Data was collected through family group interviews with 26 families. Each interview consisted of an older home dwelling cancer patient and one to four family members with different relationships to the patient (e.g. spouse, adult children and/or children-in-law). Data was analysed by qualitative content analysis.

Results: The main theme is “Non-palliative care” – health care services in the palliative phase not tailored to family needs. Three themes are revealed: 1) exhausting cancer follow-up, 2) a cry for family involvement, and 3) fragmented care.

Conclusion: The health services seem poorly organised for meeting the demands of palliative care for older home dwelling cancer patients in the palliative phase and their family members. Close family members would like to contribute but health services lack systems for involving them in the follow-up of the patient.

Keywords: Palliative care, Older, Cancer, Family caregivers, Family research, Health services

Background

Among all cancer patients in the palliative phase, $\frac{3}{4}$ have reached the age of 65 [1]. The ageing population increases the number of people afflicted with cancer [2, 3] and creates challenges for patients, families and the health care system. Due to frailty and comorbidity, older patients may need extended help [4]. For patients to remain at home, particularly in the palliative phase of their illness, family members who are willing and able to provide care are

important [5]. Particularly, available adult children and/or children-in-law may be important because the patient’s spouse might also be frail or deceased [6]. Thereby, the entire family may be affected [7, 8]. Despite these facts, there is limited research on the specific experiences and needs of cancer patients older than 65 years and their family members during the patients’ palliative phase [8, 9].

The goal of palliative care is to promote quality of life for patients and their families [10], which is in line with families’ wishes for a positive final time together [8]. To achieve this goal, relief of the patient’s physical, psychosocial, and spiritual symptoms and support for families is central. As in other Western countries, such as the USA and the UK, palliative care in Norway is highly developed

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and integrated into mainstream service provision [3, 11]. This means that palliative care should be offered wherever there may be patients with palliative care needs. Patients with cancer in the palliative phase may need regular follow-up to control symptoms and keep their cancer at bay [12]. Usually, this follow-up is monitored from hospital outpatient clinics [4, 13], such as in Norway [14]. Consequently, patients spend most of their time at home, where home care nurses (HCNs) and general practitioners (GPs) are responsible for palliative care [3, 15].

Studies have documented that older cancer patients in the palliative phase are not prioritised for palliative care [2, 9]. In addition, it is documented that older patients often have to end chemotherapy due to side effects [16, 17]. Five studies [18–22] have focused specifically on older patients' and/or their family members' experiences with the health care system. In other studies, wider ranges of patients have been studied, but the findings do not indicate any age effects related to health care system experiences [23, 24].

It seems well documented that many cancer patients in the palliative phase and their family members miss information about the illness situation, e.g., [25–27]. Information is important for family members to cope and feel safe with caregiving [25, 28, 29]. In addition, patients' and family members' dissatisfaction with coordination and continuity of care from hospitals and HCNs is well documented [19, 24, 30]. Often, family members report that they were left to coordinate care themselves [31, 32]. Additionally, studies document family members' need for support from a skilled person who knows the health care system and the family and who can coordinate and control the situation [13, 24, 33]. Some specialist palliative care interventions offer families continuity and coordination [34, 35]. Preferences regarding the professionals' personality or quality of the relationship (e.g., respect, kindness, trust, patience, and empathy) are also highlighted [23, 24, 36].

The need for family members to be “part” of the health care team is reported by both patients and family members [22, 28, 37, 38]. In addition, studies report that patients' preferences regarding their own and/or their family members' involvement in decision-making seem to vary and to change with time [39–41].

When living at home, access to health care services when needed is important [23, 30, 42]. It is also important that the services offered address the needs of patients and family members [23, 29, 43]. The older patients in Devik et al.'s (2015) study reported that HCN played an important role in provisions of palliative care. HCN may also ease caregiver burden [23, 31, 43]. However, help from HCNs can conflict with the need for independence [18, 23], dignity and the protection of the more private aspects of life [43]. Several studies reported that patients and family members perceived their GP to

lack knowledge about cancer treatment and therefore preferred to turn to their specialist at the hospital when problems arose [24, 44, 45]. For patients living in rural areas, travel to hospitals for follow-up are reported to be long and fatiguing [21, 46, 47].

The above literature review reveals some prior knowledge about individual cancer patients' and family members' experiences facing the health care system during the palliative phase. The study samples comprise older patients. However, we have not found studies that have documented findings about several family members' and the family unit's experiences and needs regarding the health care system, as all studies included have collected data through individual or focus-group interviews with patients or family members. We need more in-depth knowledge on how families experience situations in the patients' palliative phase in terms of organisation and collaboration with the health care team. Based on the descriptions and suggestions gathered from the older cancer patient and his/her family, strategies to support families in ensuring a positive final time together should be identified. The aim of this study is thus to explore what older home-dwelling cancer patients in the palliative phase and their close family members, as individuals and as a family, experience as important and difficult when interacting with health services.

Methods

The study has a qualitative design. Data were collected through family group interviews and analysed using qualitative inductive content analysis.

Sample and recruitment

A purposive sample of families was recruited. Nurses in community health services, hospital wards and outpatient clinics were asked to distribute information on the study, which included information about the researchers' goals, and to recruit patients and their family members according to the recruitment criteria. Families willing to participate either returned written consent forms or gave the nurse permission to pass on their telephone number to the interviewer. The patient or the person the family had listed as a contact person was then contacted and, if desired, given additional information on the study. The inclusion criteria were cancer patients in the palliative phase ≥ 65 years and their close family members ≥ 18 years. The included patients were required to be living at home, capable of providing informed consent and capable of participating in group interviews. Small groups of no more than 5 participants were chosen due to the families' vulnerable situations [48], because families are complex systems [49] and because it was important that the interviewer be able to lead the interviews while simultaneously observing the interactions and processes among the participants [50]. As we wanted to recruit family members with a variety of relations to the

patient, an open definition of the concept of family was adopted: “The family is who they say they are” [7]. To ensure a variety of relations in the recruitment, the interviewer discussed with the family contact person which family members were to participate, e.g., to secure sons and children-in-law in the sample. However, the final decision was left to the family.

Data collection

In family group interviews, data are collected on family members’ individual experiences and opinions as well as the family’s shared experiences and opinions [7, 51, 52]. There is very little theory available on interviewing families as a group; thus, in line with other family researchers [51], we looked to focus-group methodology for guidance. Some of the principles and understandings that focus-group research is based on are transferable to interviews of family units. However, family members are related to one another through the past, the present and the future and know each other intimately, which is generally not the case for focus-group participants [53]. As we had small groups, and the interviewer had prior experience with qualitative interview research, all interviews except one were carried out without a co-moderator [53]. The last author participated as a co-moderator in one interview to guide the interviewer.

The interviews were carried out in the patients’ homes and generally started with the drawing of a genogram, which is a diagram of the family constellation [7]. If the participants were eager to start talking, the genogram was postponed until a natural break appeared or at the end of the interview. The purpose of the genogram was to collect data on the family’s structure and to have the participants reflect on family relations (7). The interviews were based on a thematic interview guide that was developed by the authors and pilot-tested with one family. The opening question was: “How are you doing now, each of you?” Additional questions such as “How have you experienced your encounters with the health services?” and “How can the health services support your family now?” were asked. Circular questions focusing on cognitive, behavioural and emotional areas, such as “What do the rest of you think regarding what ... now says?” were used to stimulate reflections and collect data on various family members’ experiences and needs [7]. The interviews ran similar to a conversation where participants and interviewer collaborated on constructing meaning from questions and answers [54], and follow-up questions were asked by interviewer and participants to explore themes and clarify the content of what had been said.

There was typically no spokesperson in the families, possibly because the interviewer at the start of each interview told the families that both individual and common opinions and experiences are generally present in

families, and the objective was to hear all of these opinions. However, some patients would at times need some help from family members to explain what they were trying to say. Due to frailty, a few patients also rested at times while the family members talked. The interviews lasted from 90 to 120 min and were audio-recorded. The first author transcribed the first 15 interviews, and due to time constraints, the last 11 interviews were transcribed by a hired person who signed a contract, consenting that the data would be treated with confidentiality and not shared or otherwise communicated to others.

The interviewer attempted to be sensitive to and respectful of the families’ situations, emotions and reactions during the interviews. There was laughter as well as weeping, and the interviewer respected the participants if some subject was clearly avoided.

Analysis

The data were analysed using inductive content analysis, which means that codes were created openly from the text, and categories were freely generated, not from pre-determined coding sheets. Findings were related to both manifest and latent content in the material [55, 56]. The transcribed text was first read repeatedly to gain familiarity with the text and an idea of the whole picture. The text was subsequently divided into units of meaning, all with content relevant to the purpose of the study. By posing the question “What does this text say about the patients and/or the family members’ encounter with the health services?” the units of meaning were abstracted and openly coded. The codes were then evaluated in terms of differences and likenesses and categorised to create groups matching these perspectives. The groups were given names, i.e., to create categories. These categories mainly addressed the manifest content [55, 56]. To identify the latent content, the categories were further interpreted. Statements in each category were read critically and compared with other categories, codes, units of meaning and the transcribed text as a whole, and they were subjected to the following questions: “Are the experiences and opinions of the patients and the family members similar or not?” and “What is happening in the family relationships here?” Through this process, the categories were condensed into one main theme and three subthemes that described the underlying, abstract meaning of the text as a whole (see Table 1).

Trustworthiness

To convey the trustworthiness of this study, the entire research process, including recruitment, sample, data collection and data analysis, is described in detail. Conducting 26 family group interviews yielded rich and comprehensive data. The data seemed well saturated, and the final interviews did not provide new insights,

Table 1 Example of the analysis process

Theme	Exhausting cancer follow-up		A cry family involvement		Fragmented care
Categories	Patient follow-up	Exhausting traveling	Family follow-up	Information	Primary health care
Codes	Disease history	Patient travels	Knowing the system	No answers	Home care
	Elderly in hospital	Obligation to work	Advocate	Have to nag	Cancer nurses
	To be taken seriously	Latency, waiting time	Work responsibility	Allowed to ask	General practitioner
	Staff competence		Family as health care personell	Honest information	Contact
	Trail treatment plan		Family responsibility	Understandable information	Respect
	Stigmatisation		Attitudes towards health care	Different information	To be seen
			System mess	Good information	Taken seriously
			Bureaucracy	Disease information	
			Observation		

i.e., no new topics evolved through the final interviews. All the authors were female and had a preunderstanding as nurses and researchers of geriatric and cancer care and as family members. Before starting the data collection, the interviewer (the first author) reflected on her own preunderstanding of families and family relations in a palliative phase. Reflexive notes were written immediately following each interview, while listening to the interviews, during transcription and during the analysis process, with a focus on both the interviewer's role in the interviews and on the content of the interview conversations. The last 11 interviews, which were transcribed by the hired person, were carefully listened to in their entirety to ensure correct transcription. Elo et al. (2014) suggest that one researcher be responsible for the analysis. In this study, the first author was responsible for developing the process of analysis from codes to categories to themes. Then, all authors met, and the tentative codes, categories and themes were discussed and revised several times until a consensus was reached. Findings are presented with support from representative quotes to give the reader the chance to evaluate alternative interpretations. The family group interviews were conducted in Norwegian. To ensure the correct translation of quotes when transferring from spoken words during the interview to the transcribed text and to the English translation for this manuscript, the quotes were translated back to Norwegian for review by all four authors separately.

Results

Thirty-three families agreed to participate in this study. However, due to patients' deteriorated health conditions, seven families withdrew before the interview. Because the nurses who helped with recruitment approached the patients, we have no list of the families that refused to participate. The final sample consisted of 26 ethnic-Norwegian families. A total of 86 people participated in the study. See Table 2 for demographic details. Nine patients lived alone, 2

with one of their children, and the others lived with their spouse. One spouse did not participate due to poor health. Every family group interview consisted of the patient and 1 to 4 family members, with an average of 3 participants per interview. For details on the patients' cancer diagnoses and patients' and spouses' other diagnoses, see Table 3.

Many patients in this study had reduced physical capacity and some reduced mental capacity. As a result, the hospital, the HCN and the GP were often involved in the follow-up of the patients. What was important for the families in their encounters with health services was also often the most difficult, and negative experiences were more apparent in the conversations than positive experiences. The main theme in the study was "non-palliative care" – health care services in the palliative phase not tailored to family needs. The findings were divided into 3 themes: 1) exhausting cancer follow-up, 2) a cry for family involvement, and 3) fragmented care.

The findings illuminated the patients' and family members' individual opinions and experiences, the families' common experiences and the interactions within the families. The families are designated A to Z.

Exhausting cancer follow-up

Even if some patients were able to handle the cancer follow-up at the hospital well, follow-up proved exhausting for the frailest patients. Several families said the patient had become so weak in connection with tumour-directed palliative treatment that he or she had to spend 1–3 months in bed in a hospital or nursing home. Travelling to the hospital was also quite an ordeal for the frailest patients due to long distances, reduced mobility and painful symptoms. Some patients and family members thus cancelled, or did not book, follow-up appointments so that the patient would not have to travel. The following quotes from two families illustrate the level of exhaustion the cancer follow-up could cause:

Table 2 Sociodemographic characteristics of participants

Characteristics	Mean	Range
Family Members age (N = 86)		
Patients	79	(65–92)
Spouses	73	(55–84)
Sons	49	(33–56)
Daughters	46	(27–62)
Son-in-law	63	
Daughters-in-law	45	(34–53)
Grandchild	21	
Sister	65	
Characteristics	n	%
Relation of Family Member to Patient (N = 60)		
Wife	10	16
Husband	4	7
Son	11	18
Daughter	26	43
Son-in-law	1	2
Daughter-in-law	6	10
Grandchildren	1	2
Sister	1	2
Children's Marital Status (N = 37)		
Paired	24	65
Non-paired	13	35
Family Members' Educational Level (N = 60)		
High school and above	31	52
Below high school	29	48
Family Members' Employment Status (N = 60)		
Employed full-time or part-time	45	75
Retired or on sick leave or not employed	15	25

Table 3 An overview of patients' and spouses' self-reported diagnoses

Patients		Spouses	
Cancer type	Other diseases	Other diseases	
Lung	7 Cardiovascular diseases	10	4
Prostata	6 Polymyalgia	1	
Breast	1 Hearing impairment	4	1
Colon	6 Musculoskeletal diseases	9	6
Amylose	1 Mental disease	1	
Gynaecological	1 Cerebral diseases	4	2
Mole	2 Renal failure	1	1
Bone marrow	1 COPD, asthma	3	
CML	1 Diabetes	2	2
Myelomatosis	1 Vision impairment	1	
Unknown	1 Crohn's syndrome	1	

Son: «However, it was when he was given chemotherapy that he started going downhill.»

Wife: «Then, he was really sick; he couldn't even stand on his own two feet. He was in the hospital and the nursing home for almost 3 months» (family K).

Daughter: «You [the patient] avoid contacting the health services; it is just so cumbersome and difficult. I haven't pushed for hospital involvement either. I just think, no, it's too difficult, and some appointments have been cancelled» (family B).

Some patients and family members said it was better to have rewarding time at home than to suffer away from home. Other family members, however, found it disturbing not to know how the cancer was developing. The following quotes illustrate this:

Wife: «He said "No" to more therapy. The hospital called him in three times, however, and he refused, he did not want to go. He may not have lived had they convinced him to receive more treatment» (family K).

Daughter: «It would have been nice if Mom had some follow-up to see if her cancer was spreading. We don't know anything.»

Husband: «No, but I guess they figured that she would be better off doing nothing. Because then you have to travel and ... that's exhausting» (family T).

A few families had good experiences with follow-up from the GP. However, most families struggled, as most GPs in Norway do not make house calls and getting to the GP's office could be an ordeal for frailer patients, as one daughter states in the following:

«And it is not all that easy to get to the doctor's either. I really wish there was some old-fashioned family doctor available, making house calls again» (family B).

Several families expressed low confidence in the GP's competence and preferred to contact the hospital when problems arose. Low confidence seemed to be linked to experiences with the GP initially not taking the patient's complaints seriously, resulting in a delayed diagnosis. Some families thus blamed the GP for the patient's poor prognosis. The following quotes illustrate this:

Patient: «The doctor just does not really know anything about this; you should keep far away from him. You need to go to where the expertise is» (family M).

Husband: «*She's very bitter, or angry, at her doctor.*»

Patient: «*He should have seen this a long time ago*» (family Q).

When patients were unable to take a private car to the hospital, publicly organised “collective taxis” were used. These journeys were quite exhausting to many of the patients and were deemed “horrible” (patient U) and “torture” (patient M). These collective taxis must be filled, and up to 4 patients were collected at various addresses. As the following quote illustrates, the whole day may be spent travelling:

Son: «*They pick them up, driving miles and miles here, then get on the ferry and into town. Then, they may have to wait for an hour or so until all are done, and then they have to do the same rounds when they come home. It takes the whole day!*» (family L).

The roads in western Norway are often narrow, winding and bumpy, and during winter, they are also icy and slippery. This, in combination with full taxis, where patients who are not well and who do not know each other sit close to one another, added to the discomfort of the journeys. Such journeys may end in re-admittances, and the families wanted the patient to get a taxi straight home. The following quotes illustrate this:

Sister: «*In the summers, it is more or less ok, but these long trips in the winter are far worse, with all sorts of weather and wind*» (family M).

Wife: «*We travelled in a hot and full taxi; we sat so close. When we got home, the taxi driver and me pulled him into the house. Then it was just to call 113, and we were rushed back to the hospital to the doctor in an ambulance with sirens*» (family K).

Due to the hardship of travelling by the collective taxis, many families went to great lengths to provide transport for the patient. Six patients had spouses with sufficient health and a license to drive a car, and some children and/or children-in-law were able to take time off from work to drive the patient. As the quote below illustrates, being unable to drive the patient could be an emotional burden:

Daughter: «*And when he has to go to the doctor's, how are we going to get that done? We are at work, of course. Therefore, we feel guilty*» (family F).

A cry for family involvement

Many patients did not wish to, or were unable to, maintain contact with the health services and handle the information regarding their own health situation. As a result, they had more or less completely delegated that responsibility to their family members. The following two quotes and a family conversation sequence illustrate this:

Patient: «*My daughter has “taken over” me*» (family A).

Daughter: «*You don't remember well when you receive messages or things similar to that*» (family B).

Patient: «*When I'm at the doctor's, and he tries to explain something, I hardly listen to what he says.*»

Son: «*To put it like this, he gets what they say, but he never asks.*»

Wife: «*He never asks about anything.*»

Patient: «*No, I do think they should say it as it is. But that isn't all they say.*»

Son: «*That's true, and there is probably a lot you want to ask about anyway?*»

Patient: «*Maybe I am just afraid of the answer*» (family L).

The family members thus had the responsibility at home to follow up any tumour-directed palliative treatment, symptom alleviation and care and to contact the health services when problems arose, coordinate appointments, and transport the patient to such appointments. Such responsibility was accompanied by the need to be involved in the health services' follow-up of the patient. It was particularly important to be involved in the information exchange around the patient's health situation. As the quotes below illustrate, information yielded security, control and predictability:

Daughter: «*I feel that if I'm given information, I'll be able to handle it all a bit better*» (family E).

Daughter: «*It has to do with what to expect and what to consider, and what is important now and what is not*» (family B).

The family members considered the information exchange a reciprocal process. The family members had important information on the patient's symptoms and in-home resources, and the health services need this information to

provide the patient with the best possible follow-up. The following conversation among a family illustrates this:

Daughter: *«Mom may be doing ever so poorly, and then 2 days later when she is at the doctor's she says she's fine.»*

Daughter-in-law: *«And then we have to ask her, ... but how about 2 days ago?»*

Daughter: *«Then, we have to remind her»* (family N).

Family members sought information first and foremost from the hospital, but it was difficult to participate in the hospital's information exchange. Hospitals seem to primarily talk to the patients, without mapping their wishes and capacity for administering the information. As a result, as the quote below illustrates, much information is lost, which causes anxiety and unease:

Daughter: *«However, I guess they informed Mother [the patient].»*

Husband: *«Mmmm, well... I don't know about that.»*

Patient: *«No, neither do I.»*

Daughter: *«I know. That has been part of the problem too, I guess. They have given mother information, and she hasn't quite got it all»* (family I).

The family members were unfamiliar with the health care system and felt left out. They did not know what was expected of them, what to expect, or whom to contact. They learned to navigate the system only by being in the system and by trying and failing. They had learned that they had to take the initiative and often keep on asking, repeatedly, to get information. The following part of a family conversation and quotes illustrate this:

Eldest daughter: *«The admission system is not good enough.»*

Youngest daughter: *«You are just not met with openness, that it is similar to this or that. They just take it for granted»* (family N).

Daughter: *«I guess we weren't good enough at asking questions ... we did learn a LITTLE as we went along asking questions»* (family I).

The decision to delegate the responsibility to close family members was made differently among the various families. It seemed easier for the patients to delegate and for

family members to take over when a spouse or a family member had health service training. The following conversation sequence illustrates this:

Patient: *«She [daughter-in-law] is after all a trained nurse. She is ready for action. That makes me feel safe.»*

Daughter-in-law: *«And I do ask if something comes up, it may have something to do with me having a bit more knowledge about some of these things»* (family U).

As the next quote illustrates, some adult children struggled to balance the delegated responsibility with respect to the patient's autonomy and dignity:

Daughter: *«I do feel like I'm stepping a bit too closely. This is after all confidential information»* (family B).

Family members' individual information preferences in addition to the patients' information preferences might also influence the family members' search for information, illustrated by the following quotes:

Daughter: *«We don't need to know more than we need to. Therefore, we don't get nervous»* (family A).

Son: *«We have also made a point of not asking too much, so if she asks us, we don't have to lie to her»* (family G).

Doctor's appointments were seen as the most secure sources of information for the family members, which made it difficult for working children and children-in-law to obtain information. As the following quotes illustrate, family members desired a programme for paid leave from work, which would enable them to follow up their seriously ill family members:

Son: *«It is not all that easy when you work. I just now received a letter that I could not take out any more paid leave»* (family H).

Daughter-in-law: *«You can take out paid leave when the kids are sick, but it really should be the same when close family are sick»* (family U).

A series of suggestions for improving the involvement of family members in the exchange of information was made, such as inviting family participation, family conversations and alternative information channels:

Son-in-law: «Some written information from the doctor would be good.»

Daughter: «Yes, some feedback when you have been to the hospital and that it's given to us too.»

Son-in-law: «You could easily fix that confidentiality thing if he signed some letter for the family» (family B).

Daughter: «I guess it is fine that Mom [patient's wife] has been there, but I'm thinking a bit further, that I, as his daughter, could also have been there. Then, you could ask about the things that you wonder about» (family V).

Fragmented care

Most families found the health services to be fragmented. They wished to get to know the personnel who would be following them up; thus, the help could be adapted to the patient's and family members' needs and be experienced as predictable and continuous. Getting to know the personnel demands continuity among the personnel and would enable the establishment of safe and trusting relations with personnel.

Lack of continuity in the oncologist at the hospital might result in the oncologist spending the consultation time reading the patient's journal. This left little room for patients and family members to receive answers to their questions, which the following quote illustrates:

Patient: «I never had the same doctor, I've been in contact with a whole series of them. In addition, then they would spend the time reading my journal. I learned nothing new about my treatment. In addition, then I just had to leave. I felt I did not really have anything to do there» (family X).

To ensure continuity in contact with the oncologist, it was important to some families that the same family members accompany the patient every time:

Daughter: «I find it so important that the doctor knows Mom [patient]. My sister, who accompanies Mom, knows her illness history from A to Z. If I or my brother were to accompany Mom, none of us have met the doctor and we would have had to start all over again» (family N).

The families did not want HCNs to always send new people to their homes. It was particularly difficult for patients to receive care from strangers, who did not know their

needs, and this meant unpredictability concerning how help would be given. The following quotes illustrate this:

Wife: «From the HCNs, they are different every single Sunday. I do not think we would have managed if they were to be around here. However, now they don't even come in, just hand over the pills and leave» (family L).

Patient: «However, I think about those nurses, they can't really bathe me either... They can hardly touch me without me getting bruises.»

Husband: «She [patient] has some problems with some of the nurses ... it depends on who comes whether she will let them into the bathroom with her. However, now we know who those nurses are. Therefore, now even I know who might be of great help to you» (family Q).

Nine out of 26 families were followed up by a cancer nurse. The cancer nurse was the same over time and an important resource for the families. She communicated information and helped families navigate the health care system. Some families developed a trusting relationship with the cancer nurse, who thus became an important conversation partner during difficult times. Quotes from two families illustrate this:

Wife: «We get on well with the cancer nurse. We can ask her for advice and she explains different things. We trust her» (family K).

Patient: «And then she [cancer nurse] takes care of things that we can't do, such as talk to the people at the hospital» (family E).

Fragmented and unpredictable follow-up from the HCNs made the services not very attractive for many families. As a result, family members would go to great lengths to help the patient themselves. Sometimes, when the patient would want to manage without the HCNs and the family needed relief, tensions and conflicts would arise within the family, which the following quotes illustrate:

Wife: «He chases away the HCNs. He doesn't want them here. I am the 'HCN' ... » (family K).

Husband: «I criticise you a bit for not accepting more help from the home care services for your daily personal care.»

Patient: «Then, we argue a bit» (family Q).

Some families also experienced fragmented follow-up from the GP. As the following quote illustrates, the substitute doctors who did not know the patient well were more prone to sending the patient to the hospital, which led to unnecessary, exhausting journeys:

Daughter-in-law: «*They are very quick about sending the patients on, and that may be an advantage and a disadvantage both*» (family H).

Discussion

This study is, to our knowledge, the first study that specifically explores what home-dwelling older cancer patients in the palliative phase and several close family members, as individuals and as a family, experience as important and difficult when facing the health care system. Our findings suggest that for patients and family members in this study, the health services were poorly organised. First, the hospital's cancer follow-up was exhausting for many patients. Second, close family members did not feel sufficiently involved in the health services' follow-up of the patients, even if they frequently were responsible at home for keeping track of the patients' cancer follow-up. Third, the families experienced the help from the health care services as fragmented.

«Non-palliative care» to frail older cancer patients

For the frailest patients in this study, the tumour-directed palliative treatment was exhausting. Other studies have documented that chemotherapy has a more adverse effect on older patients than on younger patients [16, 17]. Earlier studies have also documented that older patients are not prioritised for palliative programmes [2, 9]. One study showed that palliative consultation led to a reduction in the use of chemotherapy in older cancer patients [57]. It may be particularly important that older patients receive follow-up from personnel who are competent in palliative care so that the cancer follow-up is adapted to the individual patient's needs and resources.

The journeys to the hospital for cancer follow-up were exhausting for the patients. This finding is also reported in a study of rural Norway [21] and in studies of rural areas of Australia and Canada [46, 47]. The findings from our study are interesting because they expand existing knowledge by showing that the journeys often became so exhausting that appointments were cancelled, and the cancer follow-up was discontinued. The journeys by collective taxi were particularly exhausting. These journeys do not appear to further the intentions of palliative care. More patients could possibly have coped better with the cancer follow-up if they travelled alone in a taxi directly between the hospital and their home.

This study shows that the frailest patients and their close family members experienced the GP as difficult to access, which was also documented in a Danish study [24]. Several families in the present study had low confidence in the GP's competence regarding the cancer follow-up, a finding also reported in several earlier studies [24, 44, 45]. It is problematic that some patients who live at home without hospital follow-up experience the follow-up from the GP as insufficient. Accessibility and competence are key factors in palliative care [58]. Care that does not include accessibility and competence may therefore be interpreted as "non-palliative care".

Lack of routines for family involvement

Our findings reveal a great need for the involvement of family in the health services follow-up of older patients. A number of studies have documented similar findings, both in patients [38, 41] and family members [28, 37, 38] and from the perspectives of family members of older patients [22]. The need for family involvement was in this study tied to the patients' incapacity to personally keep track of information and contact with the health care services. The family members in Williams et al.'s (2018) study reported similar findings; they felt compelled to navigate the patient's health services because they observed that it was challenging for the older patient to interact with the health services. It has been previously documented that older cancer patients may have difficulties remembering information and that family members help the patient recall information, ask questions and report symptoms, [39, 59, 60]. However, we have not found other studies that have reported that older patients more or less completely delegate all of their health care responsibility to close family members. This study thus shows how important it is to involve close family members in the health services' follow-up of the patient to give the patient the best possible follow-up at home and in the health services.

The findings of this study show that hospitals seem to lack routines for mapping the patient's wishes and the capacity for administering information and for involving the family when necessary and desired. Doctor's appointments and controls were described by the families as the best information channels, but for working children and children-in-law, these information channels were difficult to access. Similar results have been reported previously [23, 29]. To ensure the best possible follow-up of the patients, it is important that health services develop alternative routines for information exchange and family involvement. The family members in this study suggested family conversations, routinely attending follow up appointments with the patient, and being provided written summaries from consultations. Speice et al. (2000) argued that telephone and e-mail may also be

used. This must, of course, occur with the patient's consent. In this context, however, it is important to note that patients have described positive and negative aspects of family involvement in treatment decisions. For instance, patients do not like when family members obtain information without their knowledge or consent [39]. The relatively limited knowledge on older patients' preferences regarding family involvement indicates a need for dialogue between patients, family members and health services to map the family's expectations and the need for family involvement.

Lack of continuity – Lack of safety of care

The families found the follow-up to be fragmented, from the hospital oncologist from the GP in the municipality and from the HCN. Getting to know personnel, which depends on continuity in the personnel group, was important for the help to be adapted and predictable and to ensure the family felt safe. These findings have been well documented in earlier studies [29, 30, 41]. Continuity of care throughout the illness trajectory and across various levels in health services is the basis of palliative care [58]. This study suggests that the organisation of the health services is not in line with the principles of palliative care. The cancer nurse service was an exception and gave continuity and security to some families. Studies that evaluate palliative services (e.g., palliative ambulating teams, palliative nurse in the home) report that palliative services give patients and family members continuity and security [34, 35]. Several studies emphasise the significance of a contact person in a palliative phase [13, 24, 33]. A cancer nurse in municipal health services may constitute such a contact person. The reasons why not all families in this study were followed up by a cancer nurse may vary. As mentioned earlier, older patients are not prioritised for palliative care services [2, 9]. Additionally, the majority of the families were recruited from small municipalities where access to services and competence may be challenging. The goal of follow-up in the home, and the aim of palliative care, thus seems difficult to achieve in rural Norway [15], a tendency also seen in Australia and Canada [20].

Family involvement to support family interplay

The findings in this study show that encounters with health services can become a challenge to family life. This was especially true for the passing on of the responsibility for keeping in contact with the health services to close family members, for the patients' and family members' various information needs, and for the patients' and family members' various needs for help and support from the HCN. Cancer patients' and family members' preferences regarding content, timing, and delivery of information may vary [25, 29]. Van Eechoud, Piers, Van Camp, Grypdonck, Van den

Noortgate, Deveugele, Verbeke and Verhaeghe [61] found that when family members' wishes for involvement in older patients' advanced care planning did not agree with those of the patient, relations might become tense. We are not aware of other studies about family processes related to families' encounters with health services. The abovementioned challenges connected to family life may be related to the families' lack of knowledge of and lack of involvement in the health care system. Family members who were not trained in some health care profession did not know what was expected from them, what to expect or whom to contact. Established routines at hospitals for dialogue on expectations and need for family involvement will most likely contribute to a common understanding within the family and in meetings between the family and the health services on how the individual family should become involved to secure the best possible follow-up of the patient.

Study strengths and limitations

We wanted to recruit families with a variety of family structures, so we chose an open definition of the concept of family. Nevertheless, only families related by blood or marriage were recruited, possibly because the nurses helping with the recruitment asked only biological families or because biological families are the most common family composition among older people in rural western Norway. This could represent a study limitation, although it was difficult to avoid because other personnel performed the recruitment.

Another possible study limitation is that the transcripts were not returned to the participants for comments, nor were the findings presented to them to invite feedback on the accuracy of our interpretations. As the participants in this study were patients in the palliative phase and their closest family members, we considered that such a request would be an extra burden for them.

This study is one of few studies in the context of advanced cancer that has used family group interviews for data collection. Family group interviews in this study contributed to a new understanding of older adult cancer patients' and their closest family members' individual and shared experiences and needs in facing the health care system. It has been argued that individual interviews are most effective when the topic is sensitive. The participants may then express their feelings more openly. In our study, a few family members expressed, while standing at the door after the interview, that they withheld sensitive information so as not to burden the patient. This might also be a study limitation. However, data on how the patient passed on the responsibility of their health condition to family members seemed difficult to access in individual interviews. It is also uncertain whether the frailest patients in this study would have consented to participate in individual interviews.

Only a few of the families in our sample reported extensive challenges in relation to the health care system as a result of cancer. Because participating in research is voluntary, it is possible that families with more difficult interactions with the health care system refused to participate. Consequently, the findings must be interpreted with caution and may not be generalisable to all families in similar situations to the families studied here. However, these results and reflections may be relevant to families in similar situations.

Finally, this was a cross-sectional assessment, and a longitudinal design may have provided richer data. As the participants were in a palliative care phase, we assumed that participation in several interviews would be too tiring and thereby ethically challenging.

Conclusion

This study shows that the health services' follow-up was poorly adapted to older cancer patients in a palliative phase and their close family members' need for help and support. The organisation of the services, as well as access to services and competence within palliative care, need improvement. As long as these aspects do not function properly, it is difficult to reach the stated aims of palliative care. Routines for family involvement in the health services' follow-up of the patients when needed and wanted and providing a contact person with specialist competence in the municipality who can create continuity and predictability are suggestions to ensure that older palliative-phase patients' and their close family members' follow-up is in line with the intentions of palliative care.

Further research is needed on the experiences and needs of older cancer patients in the palliative phase and their close family members regarding the involvement of close family members in the health services follow-up of the patient, such as concerning advanced care planning and decision-making.

Abbreviations

GP: general practitioner; HCN: home care nurse

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Availability of data and materials

After completion of the study, the data will be available in the archives of research data at the Norwegian Centre for Research Data (NSD), <http://www.nsd.uib.no/data-overview.html>

Authors' contributions

MF collected the data. MF suggested the first version of codes, categories and themes. MF, GE, MK and EKG discussed the tentative codes, categories and themes in several rounds until consensus was reached. MF wrote the initial draft of this paper. EKG, MK and GE provided comments regarding all

subsequent and final versions of the paper. MF, EKG, MK and GE read and approved the final version of the paper.

Ethics approval and consent to participate

This study was conducted according to the Declaration of Helsinki (2013). The Regional Committees for Medical and Health Research Ethics approved the study: 2011/1731a. All participants were informed (both verbally and through written information) of their right to withdraw their participation at any time. All family members provided informed consent to participate in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Appendix A – Search strategy

Databases	AMED, Academic search Premium (ASP), Medline, Cinahl m/fulltekst, Psychinfo og Cochrane Library
Limitations	English language,, time period 1998-2018, adult.
	Palliative care OR end-of-life care OR terminal care OR hospice care
	AND
	Cancer OR neoplasm OR cancer patient OR cancer patients OR advanced cancer OR oncology OR tumor
	AND
General search words	Elderly OR old OR older OR old age OR older people OR patient OR patients OR care recipient OR care recipients
	AND
	Family OR families OR family member OR family members OR Caregiver OR caregivers OR relative OR relatives OR spouse OR spouses OR partner OR partners OR next-of-kin OR family caregiver OR family caregivers OR carer OR carers OR family carer OR family carers OR caregiving OR family caregiving OR primary caregiver OR primary caregiving OR Adult sibling OR adult siblings OR adult children OR adult-child caregivers
	AND
Paper 1	Relation OR relations OR relationship OR relationships OR internal relation OR internal relations OR human relation OR human relations OR relationship change* OR role OR roles OR family relationship OR family relationships OR family relation OR family relations
	AND
	Interaction OR interactions OR family interaction OR family interactions OR family functioning OR communication OR family communication OR family conflict OR family life OR family structure OR family structures OR conflict OR family conflict
	AND
Paper 2	Caregiver burden OR burden OR stress burden OR relationship burden OR distress OR stress OR caregiver distress OR caregiver stress OR family stressor OR family stressors OR caregiver reaction OR caregiver reactions OR CRA OR the Caregiver Reaction Assessment OR quality of life OR psychological health OR psychological distress OR psychological well-being OR strain OR caregiver strain OR caregiving strain OR distress OR caregiver distress OR caregiving distress
	AND
	Social support OR social provision OR social provisions OR social provisions scale OR SPS OR caregiver support
	AND
Paper 3	Health care OR health care system OR municipalities OR primary health care OR community health services OR home care services OR home care OR community-based services OR district nursing OR care settings OR formal caregiving OR formal care provision OR home-based care OR home-based palliative care OR palliative home care OR community care
	Satisfaction OR preferences OR experiences OR health care satisfaction OR health care preferences OR health care experiences OR satisfaction with care OR experiences with care
	OR service satisfaction OR service preferences OR service experiences OR Quality of health care OR quality of care OR health care quality
	AND
	Need OR needs OR unmet needs AND
	Rural OR rural living

Appendix B – Information letter



Til deg som lever med kreft og dine nærmeste pårørende

Forespørsel om å delta i forskningsprosjektet:

Hvordan eldre personer som lever med kreft og deres nærmeste pårørende opplever relasjonen til hverandre?

Hensikten med studien

Dette er et spørsmål til deg og dine nærmeste pårørende om å delta i en forskningsstudie hvor målet er å lære mer om hvordan familier som lever med kreft opplever relasjonene til hverandre. Vi trenger mer kunnskap om hvordan det er å leve med kreft, og hvordan pårørende har det i denne situasjonen. Familien er en viktig ressurs ved kreftsykdom, og helsetjenesten trenger kunnskap om hva som er viktig og hva som er vanskelig i relasjonene for å kunne hjelpe familien til å mestre situasjonen best mulig.

Studien er et doktorgradsprosjekt ved Universitetet i Oslo (UiO). Høgskolelektor, sykepleier og stipendiat Marianne Gjertsen, vil stå for gjennomføringen av intervjuet. Hovedveileder er professor Ellen Karine Grov, Høgskolen i Buskerud (HiBu). Medveiledere er professor Marit Kirkevold, UiO og førsteamanuensis Grethe Eilertsen HiBu.

Hva innebærer studien

Studien innebærer at den syke selv og inntil tre av de nærmeste pårørende blir intervjuet sammen. Den syke spør selv to til tre av sine nærmeste familiemedlemmer om å delta. Det er ønskelig at partner/ektefelle, barn og/eller barnebarn over 18 år deltar i intervjuet. Intervjuet vil være samtalepreget og vare fra en til halvannen time, og foregå der det er mest praktisk for dere.

Det er utarbeidet noen spørsmål for intervjuet, men det er deres opplevelse og erfaringer som er viktig. Å samtale om erfaringer kan være slitsomt, men kan også oppleves meningsfullt og gi nye tanker om nåværende situasjon. Dere kan avbryte og/eller be om pause når dere måtte trenge det. Dersom vi i løpet av samtalen oppdager noe som dere ønsker skal følges opp, er det på forhånd gjort avtale med kirurgisk avdeling om at de kan kontaktes.

Ved slutten av intervjuene får pårørende utlevert to spørreskjema de skal fylle ut. Disse omhandler tema vi har samtalt om. Utfyllingen av skjemaene vil ta omkring 15 minutter.

Det bes om tillatelse til å gjøre lydopptak av intervjuet. All informasjonen som gis skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter hver enkelt til deres opplysninger gjennom en navneliste. Kun stipendiaten, Marianne Gjertsen, har tilgang til navnelisten og kan finne tilbake. Lydbåndopptakene vil slettes ved avslutning av prosjektet, senest desember 2017. Det vil ikke være mulig for andre å identifisere noen av dere når resultater fra studien publiseres.

Forskerne som er involvert i studien har taushetsplikt.

Frivillighet

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta. Lydbåndopptaket vil i så fall bli slettet umiddelbart. Dette vil ikke få konsekvenser for den sykes videre behandling. Dersom dere ønsker å delta undertegner dere samtykkeerklæringen på siste side, og postlegger den i vedlagte frankerte svarkonvolutt. Det ekstra informasjonsskrivet kan dere beholde. Samtykket innebærer at dere i nærmeste framtid blir kontaktet av Marianne Gjertsen for å gjøre avtale om tid og sted for intervju.

Dersom du eller dere vurderer å delta i studien, og ønsker mer informasjon, så kan du/dere enten kontakte Marianne Gjertsen direkte, eller gi tillatelse til at sykepleier ved kirurgisk avdeling gir ditt navn og telefonnummer til henne. Marianne Gjertsen vil da kontakte deg eller dere etter fem til sju dager for ytterligere informasjon om studien. I denne perioden kan du / dere ombestemme dere og reservere dere mot å bli kontaktet av Marianne Gjertsen enten ved å gi beskjed til sykepleier på kirurgisk avdeling, eller ved å kontakte Marianne Gjertsen via telefon, post eller e-post. Når Marianne Gjertsen mottar skriftlig samtykkeskjema, tar hun kontakt for å gjøre avtale om tid og sted for intervju.

Studien er anbefalt iverksatt av Regional Komité for medisinsk forskningsetikk.

Dersom dere har spørsmål eller ønsker flere opplysninger kan dere kontakte Marianne Gjertsen på telefon

57 72 25 10 eller 95 91 17 70, eller e-post marianne.gjertsen@hisf.no

Med vennlig hilsen

Marianne Gjertsen
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Appendix C – Consent form

SAMTYKKEERKLÆRING

Vi samtykker i å delta i stipendiat Marianne Gjertsen's doktorgradsprosjekt:

"Hvordan opplever eldre hjemmeboende personer som lever med kreft og deres nærmeste pårørende relasjonen til hverandre"?

Vi har lest informasjonsskrivet med forespørsel om deltakelse og erklærer at vi er villig til å delta i familieintervju.

Sted, den

Pasient: Telefon nummer:

Familiemedlem: Telefon nummer:

Familiemedlem: Telefon nummer:

Familiemedlem: Telefon nummer:

Når passer det best å gjennomføre intervju: ukedag, tidspunkt :

.....

Underskrift stipendiat Marianne Gjertsen

Appendix D – Interview guide

DATASAMLINGSGUIDE

1. GENOGRAM

Først vil jeg gjerne tegne et familietre sammen med dere for å få vite mer om hvem dere er. Det jeg da trenger opplysninger om er partnere/ektefelle og de som er gått bort eller skilt fra hverandre, barn, barnebarn inklusiv alder, kjønn, skole/utdanning/jobb og hvor langt fra den syke bor.

Er der noen dere regner som nær familie som ikke er biologisk familie?

Diagnose(r), hvor lenge vært syk, tid siden spredning.....

Familiemedlemmer har ofte ulik grad av nærhet/kontakt med hverandre. Dette kan vises med antall streker mellom medlemmene i familietreet, hvor tre streker er tett kontakt og en strek er sporadisk kontakt. En stiplet strek angir vanskelig kontakt og kryss over streken vil si brutt kontakt.

2. HVORDAN HAR DERE DET I FORHOLD TIL HVERANDRE NÅ NÅR ER SYK?

- a. Hva er viktig for dere nå når er syk?
- b. Har det som nå er viktig endret seg etter at ble syk?
- c. Hva er vanskelig for dere nå når er syk?
- d. Har det som nå er vanskelig endret seg etter at ble syk?
- e. Er det noe dere skulle ønske var annerledes dere imellom?
- f. Dere har ulike familieroller overfor (den syke); partner, barn, barnebarn etc. Varierer hva som er viktig avhengig av hvilken familierolle en har til den syke? Hvordan? Hva med det som er vanskelig?
- g. Hva er viktig og vanskelig i pårørendes /barnas eget familieliv når når Er syk?

3. OPPGAVE OG ROLLEFORDELING

- a. Hvilken hjelp og støtte trenger (den syke) nå?
(ADL, praktiske oppgaver; transport, husarbeid, handling, hage og vedlikehold etc.
Emosjonell støtte, sosial kontakt etc)

- b. Hvem gir (den syke) denne hjelpen og støtten? Flere som er involvert? Hvem hjelper med hva?
- c. Hva er det som gjør at akkurat hjelper (den syke) mest?
- d. Hvis (nærmeste omsorgsperson) ikke kunne hatt denne rollen, hva ville da skje? Ville noen andre i familien kunne hatt denne rollen?
- e. Er det andre personer utenfor den nærmeste familien dere anses som ressurser for dere nå? (nyttiggjøre seg nettverket).
- f. På hvilke måter har dere funnet å klare å snakke sammen om situasjonen?
- g. Er det noe dere skulle ønske var annerledes ifht den oppgave- og rollefordeling dere nå har?

4. AVHENGIG AV HJELP/BYRDE/BELASTNING

- a. Hvordan opplever du (den syke) å nå måtte ha hjelp med ting du tidligere har klart selv?
- b. Hva tenker dere andre om det (den syke) sier nå?
- c. Hvordan opplever (nærmeste omsorgsperson(er) – kan være flere) rollen som hjelper for den syke?
- d. Hvilken hjelp og støtte får/trenger du/dere (nærmeste omsorgsperson(er)) til å fylle rollen? (Fra familie, venner, helsetjenesten etc).
- e. Hva tenker dere andre om det (nærmeste omsorgsperson) sier nå?
- f. Hvordan opplever dere at andre utenfor nærmeste familie tar kontakt for å høre hvordan det går med (den syke)?
- g. Hvordan opplever dere at andre utenfor nærmeste familie tar kontakt og spør hvordan det går med dere som pårørende nå når er syk?
- h. Er det en som har tatt på seg å være kontaktperson overfor de som ringer eller tar kontakt? Hvordan har denne oppgaven vært for deg?

5. HELSETJENESTEN

- a. På hvilke måter kan helsetjenesten støtte dere som familie nå?

6. AVSLUTNING

- a. Er det noe vi ikke har vært innom som dere tenker er viktig for å forstå hvordan det er å være både enkeltpersoner og en familie i den situasjonen dere alle er i nå?

TUSEN TAKK TIL HVER ENKELT FOR AT DU VILLE DELTA I DENNE SAMTALEN!

Appendix E – The caregiver Reaction Assessment

1. I feel privileged to care for __.
2. Others have dumped caring for __ onto me.
3. My financial resources are adequate to pay for things that are required for caregiving.
4. My activities are centered around care for __.
5. Since caring for __, it seems like I'm tired all of the time.
6. It is very difficult to get help from my family in taking care of __.
7. *I resent having to take care of __.
8. I have to stop in the middle of work.
9. I really want to care for __.
10. My health has gotten worse since I've been caring for __.
11. I visit family and friends less since I have been caring for __.
12. I will never be able to do enough caregiving to repay__.
13. *My family works together at caring for __.
14. I have eliminated things from my schedule since caring for __.
15. *I have enough physical strength to care for __.
16. Since caring for __, I feel my family has abandoned me.
17. Caring for __ makes me feel good.
18. The constant interruptions make it difficult to find time for relaxation.
19. *I am healthy enough to care for __.
20. Caring for __ is important to me.
21. Caring for __ has put a financial strain on the family.
22. My family (brothers, sisters, children) left me alone to care for __.
23. I enjoy caring for __.
24. It's difficult to pay for __'s health needs and services.

The response format for the above questions is as follows:

1. = Strongly disagree
2. = Disagree
3. = Neither agree nor disagree
4. = Agree
5. = Strongly agree

*These questions are to be reverse scored

SPØRSMÅL VEDRØRENDE PLEIE- OG OMSORGSGIVERS REAKSJON/SITUASJON

Vennligst les gjennom hvert punkt og sett en ring rundt det tallet som best beskriver din reaksjon/situasjon i rollen som pleie- og omsorgsyter akkurat nå.

	Helt enig	Enig	Verken enig eller uenig	Uenig	Helt uenig
1. Jeg er svært takknemlig for at jeg får pleie__.	5	4	3	2	1
2. Andre har lempet pleien av __over på meg.	5	4	3	2	1
3. *Min økonomi er tilstrekkelig til å betale for de ting som er nødvendig for pleien.	5	4	3	2	1
4. Mine aktiviteter dreier seg om pleie av __.	5	4	3	2	1
5. Etter at jeg begynte å pleie __, virker det som om jeg alltid er sliten.	5	4	3	2	1
6. Det er svært vanskelig å få familien min til å hjelpe meg med å pleie __.	5	4	3	2	1
7. *Jeg misliker å pleie __.	5	4	3	2	1
8. Jeg må avbryte det jeg holder på med.	5	4	3	2	1
9. Jeg ønsker virkelig å pleie __.	5	4	3	2	1

10. Helsen min er blitt dårligere etter at jeg begynte å pleie __.	5	4	3	2	1
11. Jeg besøker familie og venner sjeldnere etter at jeg begynte å pleie __.	5	4	3	2	1
12. Jeg vil aldri kunne yte nok pleie for å gjøre gjengjeld overfor __.	5	4	3	2	1
13. *Familien min samarbeider om å pleie __.	5	4	3	2	1
14. Jeg har kuttet ut noen av de tingene jeg pleide å gjøre, etter at jeg begynte å pleie __.	5	4	3	2	1
15. *Jeg har tilstrekkelig fysisk styrke til å pleie __.	5	4	3	2	1
16. Etter at jeg begynte å pleie __, føler jeg at familien min har sviktet meg.	5	4	3	2	1
17. Å pleie __, får meg til å føle meg vel.	5	4	3	2	1
18. Avbrytelsene hele tiden gjør det vanskelig å få tid til å slappe av.	5	4	3	2	1
19. *Jeg er frisk nok til å pleie __.	5	4	3	2	1
20. Å pleie __, er viktig for meg.	5	4	3	2	1
21. Å pleie __, har gjort familiens økonomi anstrengt.	5	4	3	2	1

22. Familien min (brødre, søstre og barn) har overlatt det til meg alene å pleie ___.	5	4	3	2	1
23. Jeg trives med å pleie .	5	4	3	2	1
24. Jeg har vanskeligheter med å betale for det ___ trenger av helsebehov og -tjenester.	5	4	3	2	1

Appendix F – The Social Provisions Scale

1). Reassurance of worth:

- 5. I do not think other people respect my skills and abilities
- 7. I have relationships where my competence and skill are recognized
- 10. Other people do not view me as competent
- 13. There are people who admire my talents and abilities

2). Attachment:

- 2. I feel that I do not have close personal relationships with other people
- 11. I have close relationships that provide me with a sense of emotional security and well-being
- 12. I feel a strong emotional bond with at least one other person
- 14. Lack a feeling of intimacy with another person

3). Nurturance:

- 1. There are people who depend on me for help
- 3. I feel personally responsible for the well-being of another person
- 9. There is no one who really relies on me for their well-being
- 16. No one needs me to care for them

4). Social integration:

- 4. I feel part of a group of people who share my attitudes and beliefs
- 6. There are people who enjoy the same social activities as I do
- 8. There is no one who likes my interests and concerns
- 15. There is no one who likes to do the things I do.

Sosial støtte skala

Alle mennesker har sin egen oppfatning om ulike ting. Nå følger en del påstander og spørsmål som handler om holdninger, interesser og følelser. Det finnes ikke noe "rett" eller "galt" svar. Ditt svar beskriver bare hvorledes du tenker og føler i ulike situasjoner. Visse påstander eller spørsmål kan føles fremmede, men forsøk å besvare dem allikevel. Spørsmålene gjelder hvordan du føler deg akkurat nå.

	Stemmer helt	Stemmer delvis	Stemmer knapt	Stemmer ikke
1. Det finnes personer som er avhengige av min hjelp	4	3	2	1
2. Det føles som om jeg ikke har nære personlige relasjoner med andre mennesker	4	3	2	1
3. Jeg kjenner meg personlig ansvarlig for et annet menneskes velbefinnende	4	3	2	1
4. Jeg føler at andre i min omgangskrets deler mine synspunkter	4	3	2	1
5. Det føles som om andre mennesker ikke respekterer det jeg kan	4	3	2	1
6. Jeg kjenner personer som liker de samme sosiale aktiviteter som meg	4	3	2	1
7. Jeg har bekjente som verdsetter min dyktighet og mine kunnskaper	4	3	2	1
8. Det finnes ingen som deler mine interesser og det som angår meg	4	3	2	1
9. Det er ingen som er avhengig av meg for sitt velbefinnende	4	3	2	1
10. Det føles som om andre mennesker betrakter meg som udugelig	4	3	2	1
11. Det finnes mennesker som gir meg en følelse av trygghet og velbefinnende	4	3	2	1
12. Jeg kjenner en sterk følelsesmessig nærhet til minst et annet menneske	4	3	2	1
13. Det finnes personer som setter pris på mine muligheter og evner	4	3	2	1

14. Det finnes ingen som jeg kan stole på	4	3	2	1
15. Jeg kjenner ingen som liker å gjøre det samme som meg	4	3	2	1
16. Ingen trenger lenger min omtanke og omsorg	4	3	2	1

Appendix G – Demographic questions

Dato for utfylling

Pårørende ref.

Dag Mnd År

Kjønn: Kvinne Mann

Alder: (hele år)

Tilknytning til pasienten (pårørenderolle):

Geografisk avstand til pasientens bopel (km):

Sivil status

Hva er din nåværende sivilstatus

Aldri vært gift

Gift/samboende

Enkemann/enke

Separert/skilt

Arbeid og utdanning

Hvilken utdanning er den høyeste du har fullført?

Grunnskole 7-10 år, framhaldskole, folkehøgskole

Realskole, middelskole, yrkesskole 1-2 årig

Artium, øk. Gymnas, allmennfaglig retning

Høgskole/universitet mindre enn 4 år

Høgskole/universitet 4 år eller mer

Hva er din nåværende arbeidssituasjon?

- | | |
|--|---|
| <input type="checkbox"/> Arbeidsledig/permittert | <input type="checkbox"/> I fullt arbeid |
| <input type="checkbox"/> Sykemeldt | <input type="checkbox"/> Alderspensjonist |
| <input type="checkbox"/> Attføring | <input type="checkbox"/> Utdanning, militærtjeneste |
| <input type="checkbox"/> Uføretrygdet | <input type="checkbox"/> Hjemmeværende/husarbeid |
| <input type="checkbox"/> Delvis i arbeid | |

Mottar du noen av følgende offentlige ytelser?

Ja Nei

- | | | |
|---|--------------------------|--------------------------|
| a) Sykepenger/ syk lønn/ rehabilitering | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Ytelser under yrkesrettet attføring | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Uførepensjon | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Alderspensjon | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Sosial støtte | <input type="checkbox"/> | <input type="checkbox"/> |
| f) Arbeidsledighetstrygd | <input type="checkbox"/> | <input type="checkbox"/> |
| g) Overgangsstønad | <input type="checkbox"/> | <input type="checkbox"/> |
| h) Etterlattepensjon | <input type="checkbox"/> | <input type="checkbox"/> |
| i) Andre ytelser, omsorgspenger | <input type="checkbox"/> | <input type="checkbox"/> |

Stort sett, vil du si at din helse er:

- Utmerket
- Meget god
- God
- Nokså god
- Dårlig

Sammenlignet med for ett år siden, hvordan vil du si at helsen din stort sett er nå?

- Mye bedre nå enn for ett år siden
- Litt bedre nå enn for ett år siden
- Omtrent den samme som for ett år siden
- Litt dårligere nå enn for ett år siden
- Mye dårligere nå enn for ett år siden

Appendix H – Approval from the regional ethical committee (REK)



Region: REK sør-øst A
Saksbehandler: Jørgen Hardang
Telefon: 22845516

Vår dato: 13.10.2011
Vår referanse: 2011/1731
Deres dato:
Deres referanse:

Ellen Karine Grov
Høgskolen i Buskerud

2011/1731a Relasjoners betydning i kreftforløpets palliative fase

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk i møtet 22. september 2011. Søknaden er vurdert i henhold til lov av 20. juni 2008 nr. 44, om medisinsk og helsefaglig forskning (helseforskningsloven) kapittel 3, med tilhørende forskrift om organisering av medisinsk og helsefaglig forskning av 1. juli 2009 nr 0955.

Prosjektleder: Ellen Karine Grov

Forskningsansvarlig: Høgskolen i Sogn og Fjordane

Hensikten med denne undersøkelsen er ”å utvikle kunnskap om hvordan eldre hjemmeboende kreftpasienter og deres nærmeste pårørende opplever relasjonen til hverandre i livets siste fase”.

Det planlegges å benytte kvantitative og kvalitative data. Kvantitative data om relasjoner, kjønnsforskjeller og pårørendes pleie- og omsorgssituasjon innhentes ved to spørreskjemaer (Social Provision Scale” og ”The Caregiver Reaction Assessment”) som er oversatt til norsk og validert. Det skal gjennomføres familieintervju etter modell av fokusgruppeintervju for å få kvalitative data.

Til undersøkelsen tar en sikte på å rekruttere 20 - 30 kreftpasienter i palliativ fase med estimert levetid inntil 6 måneder. I tillegg kommer 2 – 3 av de nærmest pårørende. Deltakerne skal rekrutteres fra både spesialist- og kommunehelsetjenesten.

Slik prosjektopplegget er beskrevet i søknaden har komiteen ingen innvendinger til at prosjektet gjennomføres.

Vedtak:

Komiteen godkjenner at prosjektet gjennomføres i samsvar med det som framgår av søknaden.

Godkjenningen gjelder til 1.1.2017.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren». Personidentifiserbare data slettes straks det ikke lenger er behov for dem og senest ved prosjektets avslutning.

Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Prosjektet skal sende sluttmelding på eget skjema, se helseforskningsloven § 12, senest et halvt år etter prosjektslutt.

Besøksadresse:
Gullhaug torg 4A
0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: <http://helseforskning.etikkom.no>

Vi ber om at alle henvendelser sendes inn via vår saksportal eller på e-post. Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Gunnar Nicolaysen
professor dr. med.
leder

Jørgen Hardang
seniorrådgiver

Kopi: Høgskolen i Sogn og Fjordane ved øverste administrative ledelse: post@hisf.no;
eva.halvorsen@hisf.no

Besøksadresse:
Gullhaug torg 4A
0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: <http://helseforskning.etikkom.no>

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