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Doctoral thesis

NTNU
Norwegian University of Science and Technology
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Content

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List of included papers

This thesis is based on the following three studies:

Sub study I Tarberg, A.S., Kvangarsnes, M., Hole, T., Thronæs, M., Madssen, T.S., & Landstad, B.J. (2019). Silent voices- Family caregivers narratives of involvement in palliative care. *Nursing open, 6(4), 1446-1454.* https://doi.org/101002/nop2.334

Sub study II Tarberg, A.S., Landstad, B.J., Hole, T., Thronæs, M., & Kvangarsnes, M. (2020). Nurses experiences of compassionate care in the palliative pathway. *Journal of Clinical nursing, 29 (23-24), 4818-4826.* https://doi.org/10.1111/jocn.15528

Sub study III Tarberg, A.S., Thronæs M., Landstad BJ., Kvangarsnes M., Hole, T. Physicians' perceptions of patient participation and involvement of family caregivers in the palliative care pathway in Norway. *Health expectation.* https://doi.org/10.1111/hex.13551

Abbreviations

NMP	New public management
ACP	Advanced care planning
GP	General Practitioner
CC	Cancer coordinator
CAT	Carers Alert Thermometer
CSNAT	The Carer Support Needs Assessment Tool

Samandrag

Hensikta med denne avhandlinga var å utvikle kunnskap om pasientmedverknad, familieinvolvering og “compassionate care” i dei ulike fasane av det palliative forløpet sett frå perspektiva til pårørande og helsepersonell. Verdens Helseorganisasjon anslår at omlag 40 millionar menneske har behov for palliativ behandling kvart år. Dette talet på pasientar som har behov for palliativ behandling vil auke, og der er politiske føringar for meir heimetid og for død i heimen. Det vil føre til at pårørande kan får ekstra stor omsorgsbyrde. Pasientmedverknad, familieinvolvering og «compassionate care» er viktig i det palliative forløpet.

Ulike teoretiske perspektiv vart valt i studiane: pasientmedverknad/-involvering, «compassionate care» og dei fire prinsippa for biomedisinsk etikk. Etymologisk har dei ulike begrepa ulike røter, men også fellestrekk. Forskningsspørsmåla og dei teoretiske perspektiva vart tilpassa de ulike gruppene som er studerte. Den første studien såg på pårørande si erfaring med informasjon og involvering. Den andre studien såg på sjukepleiarar si erfaring med «compassionate care» for pasientar og pårørande. Den tredje studien undersøkte legars perspektiv på pasientmedverknad og pårørandeinnvolvering.

I dette forskingsprosjektet har vi brukt ulike kvalitative tilnærmingar som vi såg som relevante utifrå forskingsspørsmåla og hensikta med studiane. I studie I hadde vi ei narrativ tilnærming, og i studie II og III ei hermeneutisk tilnærming. Deltakarane var frå både urbane og rurale strok i Norge, og hadde erfaring i frå dei ulike fasane av det palliative forløpet. Det vart gjennomført 11 individuelle intervju med dei pårørande, 13 intervju med legar og fire fokusgrupper med sjukepleiarar. Funna frå dei tre primærstudiane vart syntetisert til tre nye temaa i avhandlinga.

Tidleg involvering og profesjonelle beslutningar. Sjukepleiarane framheva betydinga av tidleg dialog mellom pasientar, pårørande og helsepersonell og meinte at tidleg involvering auka vilkåra for å kunne yte omsorgsfull behandling seinare i forløpet. Tverrfagleg samarbeid mellom spesialisthelsetenesta og primærhelsetenesta vart sett på som viktig for å betre omsorga. Pårørande gav uttrykk for at sjølv om dei var godt informert om pasienten si diagnose, opplevde dei lite involvering i prosessen med å definere problema og utfordringar knytt til behandlinga av pasienten. Dei ønska meir informasjon om korleis sjukdommen

kunne utvikle seg, og kva dei kunne forvente ville oppstå i dei ulike fasane av forløpet. Legane beskreiv den tidlege fasa som krevjande for pasientar og pårørande. Dei gav uttrykk for at behandlingsval i denne fasa ofte vart gjort av legane fordi pasienten og pårørande var i en sårbar situasjon. Legane var opptekne av å gjere det dei trudde ville være til det beste for pasienten og pårørande.

Pasientsentrert omsorg og manglande anerkjenning av pårørande. Midtfasa var prega av pasientsentrert omsorg og samval. Helsepersonell ønskte å vere i forkant av utfordringar som kunne kome og gi pasientar og pårørande tryggleik og avklaringar. Det vart sett på som viktig å være merksam på pasientane og pårørande sine psykiske og fysiske behov. Å skape eit rom for å døy vart også framheva. Pårørande opplevde denne fasa som pasientsentrert, men dei opplevde samtidig at denne fasa kunne vere svært stressande der dei tok på seg ei omsorgsrolle som gjorde det vanskeleg å ivareta rolla som pårørande. Dei ga uttrykk for at deira eigne behov som pårørande ofte vart neglisjert. Sjukepleiarane og legane fortalte at å balansere mellom konfliktar hos pasientar og pårørande kunne vere ei utfordring i denne fasa.

Pårørande si involvering i omsorg og aksept av døden. Pårørande omtala denne fasa som utfordrande då dei fleste av dei ikkje hadde opplevd død tidlegare, og dei kjende seg usikre på kva som ville skje. Dei fekk lite informasjon om dødsprosessen, og nokre pårørande kjende seg åleine med ansvaret og byrda. Sjukepleiarane og legane framheva betydinga av å gi informasjon både til pasientar og pårørande. Pårørande erfarte at dei var sterkt involverte i denne fasa, og dei var ofte slitne; det å få informasjon om behandling var avgjerande for å kunne forstå og meistre situasjonen. Legane erfarte at pårørande som kjende seg involvert i det palliative forløpet, kjende seg tryggare og kunne få ein mildare sorgprosess. Pårørande, sjukepleiarar og legar beskreiv etterlattesamtale som viktige, spesielt i tilfelle med krevjande dødsprosessar.

Denne avhandlinga gir ny kunnskap om pasientmedverknad, familieinvolvering og «compassionate care» for pasientar og pårørande i dei ulike fasane av det palliative forløpet. Et viktig funn er at pårørande opplever manglande involvering gjennom heile forløpet. Dei opplever å ikkje verte sett på som en del av det palliative behandlingsteamet. Avhandlinga reiser også nye spørsmål: Korleis påverkar fokuset på pasientsentrert omsorg pårørande? Å overføre ansvar i palliasjon til pårørande krev forsking som belyser pårørande sin situasjon.

Summary

The overall aim of this thesis was to obtain knowledge about patient participation, family involvement, and compassionate care as experienced by family caregivers and health personnel in the different phases of the palliative cancer care pathway. According to the World Health Organization it is estimated that approximately 40 million people need palliative care each year. The number of patients needing palliative care will increase, and the political documents call for more patients to remain at home and die at home. More time at home and home death will mean family caregivers will experience additional burdens linked to caring for patients. Patient participation, family involvement, and Compassionate care is crucial in the palliative pathway.

Various theoretical frameworks were chosen in the studies: patient participation/ involvement, compassionate care, and the four principles of biomedical ethics. Etymologically the various concepts have different roots, but they still have common features. The research questions and theories were adapted to the different groups of participants under study. The first study explored how family caregivers experience information and involvement. The second study explored nurses' experiences of compassionate care for patients and family caregivers. The third study explored physicians' perspectives of patients' participation and family caregivers' involvement.

In this research project, we have used different qualitative approaches appropriate for the research questions and aims of the studies. In Study I, we adopted a narrative approach, and in Studies II and III a hermeneutic approach. We employed purposive sampling, and participants with experience from various phases of the palliative pathway were chosen. Eleven family caregivers and thirty-four health personnel from rural and urban areas in Norway participated. Individual interviews with family caregivers and physicians, and four focus groups with nurses were conducted. The findings from the three primary studies were synthesised into three new themes in the thesis.

Early involvement and professional decisions. The nurses highlighted the importance of early dialogue between patients, family caregivers, and healthcare personnel, and felt that early involvement increased their ability to provide compassionate care. Interdisciplinary collaboration between specialist healthcare services and primary healthcare was considered important to improve compassionate care. Family caregivers expressed that although they

were well informed about the patient's diagnosis, they experienced low involvement in defining problems and challenges regarding the care of the patient. They wanted more information about how the disease would develop and what to expect in the different phases of the pathway. The physicians described the early phase as demanding for patients and family caregivers. They expressed that treatment choices in this phase were often made by the physicians because the patient and family caregivers were in a vulnerable situation. The physicians were concerned with doing what they thought would benefit the patient and family caregivers.

Patient-centred care and lack of acknowledgement of family caregivers. The middle phase was characterised by patient-centred care and shared decision-making, and patients and family caregivers were provided with security, predictability, and clarification. It was seen as important to be aware of patients' and family caregivers' mental and physical needs. Creating a space for dying was also highlighted. Family caregivers experienced this phase as patient-centred, but they also found it to be a very stressful phase in which they took on a caregiving role rather than a role as a family member. They expressed that their own needs as family caregivers were often neglected. Nurses and physicians sometimes described balancing conflicts among patients and family caregivers as challenging in this phase.

Family caregivers' involvement in care and acceptance of death. Family caregivers described this phase as challenging as most of them had not experienced death before, and they felt insecure about what would happen. They received little information about the death process, and some family caregivers felt alone with the responsibility and burden. Nurses and physicians highlighted the importance of providing information both to patients and family caregivers. Family caregivers were strongly involved in this phase, and they were often tired; receiving information about treatment was essential for them in coping and understanding what had been decided. The physicians expected that family caregivers who were involved in the palliative process would endure a softer grieving process and feel more secure. The family caregivers, nurses, and physicians all described bereavement conversations as important, especially in cases with demanding death processes.

This thesis provides new knowledge of patient participation, family involvement, and compassionate care for patients and family caregivers in various phases of the palliative pathway. An important finding is that family caregivers experience a lack of involvement throughout the process. They do not experience to be seen as part of the palliative care around the patient. The thesis also raises new questions: How does the focus on patient-centred care affect family caregivers? Transferring responsibility in palliative care to family caregivers requires research that sheds better light on family caregivers' situation.

Situating my position

My nursing experience is in primary care, in which I have practised for 30 years, 12 of which I spent as an oncologic nurse. Working closely with palliative care patients and their family caregivers has played a substantial role in my choice of research field. Palliative care has always been my field of interest. In my bachelor's thesis, I wrote about home death, and for my master's thesis, I interviewed leading health personnel about palliative care in the municipalities (Tarberg et al., 2016). While writing my master's thesis, I started reflecting and asking questions, and this is how the PhD process began; I wanted to interview people closest to the patient pathway 'those walking in the shoes'. Further, I wanted to follow the entire pathway, including the follow-up period after death.

My earlier work sharpened my curiosity about family caregivers', nurses', and physicians' experiences with the palliative care pathway, and I wanted to understand more. Qualitative research became the apparent choice for seeking multiple truths and interpreting different perspectives and experiences (Creswell, 2014; Patton, 2002).

At the beginning of my PhD journey, I did not fully understand what lay ahead of me. I have depended upon my supervisors to help design studies and make choices. Accordingly, this thesis is also shaped by my supervisors' experiences, knowledge, and background.

1 Introduction

The number of patients needing palliative care will increase, and the government policy is to encourage more patients to remain home longer and die at home (Helse- og omsorgsdepartementet, 2009; NOU 2017:16, 2017; World Health Organization, 2016, 2016-2020). The WHO defines palliative care as 'an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial or spiritual' (World Health Organization, 2020). These general principles for palliative care are relevant to all types of diagnoses. In this research project we explore palliative care for cancer patients.

Cancer statistics estimate that there were 10 million cancer deaths in 2020 (Ferlay et al., 2021) and 19.3 million new cancer cases (Sung et al., 2021). Furthermore, research acknowledges cancer as a leading cause of premature death worldwide (Bray et al., 2021), and approximately 40 million people need palliative care each year (World Health Organization, 2020). A recent review study revealed that more than half of cancer patients in the later stages of life prefer to die at home (Fereidouni et al., 2021). Subsequently, family caregivers will shoulder challenging burdens in palliative care (Andershed, 2006; Funk et al., 2010; McDonald et al., 2018; Naoki et al., 2018; Røen, 2022; Stajduhar et al., 2010), and the WHO's (2018a) definition of palliative care emphasises the needs of the families involved.

Introducing palliative care early in the disease trajectory has showed earlier symptom identification and treatment (Verkissen et al., 2019). Earlier integration of palliative care, is recommended to promote better treatment and care, enhance quality of life, and decrease symptom burden (Finn et al., 2017; Kaasa et al., 2018). This early involvement seems to lead to a lower percentage of hospital deaths and less aggressive end-of-life care treatment. In addition, patients and family caregivers show higher satisfaction rates, and family caregivers seem to feel less angry and engage less often in denial of the anticipated death of their loved one (Hui et al., 2018).

The overall aim of this thesis was to obtain knowledge about patient participation, family involvement, and compassionate care as experienced by family caregivers and health personnel in the different phases of the palliative cancer care pathway. Patient participation and family involvement are crucial elements of high-quality palliative care (Bélanger et al., 2016; Kaasa et al., 2018; Schram et al., 2017; Wakefield et al., 2018). Previous research suggests that these are essential areas in palliative cancer care (Finn et al., 2017; Hui et al., 2018; Kaasa et al., 2018).

We have chosen several theoretical frameworks for this research project to study palliative cancer care. We initially thought that patient participation should be the only theoretical framework. However, during the work, we recognised that the theory of compassionate care could be appropriate to highlight key findings from our interviews with the nurses. The relationship between patient participation and compassionate care is explained in Chapter 3. Here, I briefly clarify my understanding of these concepts.

Patient participation

Internationally, patient participation is legislated and recognised as a critical factor in the healthcare system (Giusti et al., 2020; World Health Organization, 2013). In Norway, patients' and family caregivers' rights to information and participation are regulated through the Patient and User Rights Act (1999). The patient has the right to participate in the choice between available and justifiable forms of service and examination and treatment methods. The degree of participation must be adapted to the individual's ability to give and receive information (Norwegian Ministery of Health and Care Service-Patients and User Rights Act, 1999). Patient participation is justified based on democratic values and the patient's legal rights (Collins et al., 2007; Landstad et al., 2020; Norwegian Ministery of Health and Care Service-Patients and User Rights Act, 1999; Nylenna, 2020). Increased patient participation seems to result in more satisfied patients, better interaction between healthcare personnel and patients, strengthened ability to cope with illness, increased patient safety, and fewer complaints about the healthcare system (Collins et al., 2007; Vahdat et al., 2014). In the Shanghai declaration, individuals' empowerment and participation in their healthcare are promoted (World Health Organization, 2018b).

Patient participation is recognised as a key component in healthcare (Longtin et al., 2010), and internationally, patient participation is recognised as a critical factor in severe illness in healthcare (Giusti et al., 2020; World Health Organization, 2013). Moreover, participation in healthcare is essential for the self-management of chronic illnesses (Protheroe et al., 2013). Patient participation and involvement have gained increasing prominence in health care and have been prioritised in policy initiatives (Collins et al., 2007; Thompson et al., 2007; Thompson, 2007).

Patient participation is a complex matter that occurs through relationships and dialogue (Arnstein, 1969; Thompson et al., 2007; Thompson, 2007; Tritter, 2009). Healthcare primarily concerns patients, family caregivers, and health personnel looking after patients' interests. However, patients experience illness in body and mind, and they, along with their family caregivers, must live with the consequences of different treatment choices. Therefore, health professionals must listen to their insights and experiences (Landstad, Bårdsgjerde, et al., 2020; Thompson et al., 2007; Thompson, 2007). In high-quality care, understanding the patient's care goals within the context of serious illness is essential (Bernacki & Block, 2014; Phillips et al., 2019).

In a recent review, Noteboom et al. (2021) found that patients' preferences regarding involvement in cancer treatment decision-making vary, but that most prefer to be involved. However, patients may experience a different role from their preferred one, especially when they prefer a shared role. Moreover, there is still room for improvement, and physicians should be more aware of the importance of exploring patients' preferences for involvement in decision-making to deliver personalised cancer care (Bernacki & Block, 2014; Noteboom et al., 2021).

It can be challenging for health personnel to meet patients' expectations of involvement. Furthermore, there is little consensus about what participation means, how it works, and how to execute it (Brogan et al., 2018; Collins et al., 2007). Healthcare personnel are influenced by several issues in the promotion of patient participation in the context of chronic illness: a desire to maintain control; the time required to educate and respond to patients; the type of illness; personal beliefs; and the healthcare professional's speciality, ethnic origin, and level of training in patient participation (Longtin et al., 2010).

There are various definitions of patient participation (Arnstein, 1969; Barello et al., 2012; Castro et al., 2016; Sahlsten et al., 2008; Thompson et al., 2007). In this thesis, we have chosen to use the framework developed by Andrew Thompson et al. (2007), which is relevant to studying participation and involvement in clinical work. Thomson states that participation can be understood in terms of components, levels, and context and that a distinction should be made between the desired levels of participation and those achieved. Furthermore, participation can be understood only in the context of specific settings and types of consultations (Thompson et al., 2007). Thompson’s framework is explained in a complementary way in Chapter 3.

Compassionate care

Throughout nursing history, compassion has been viewed as a quality associated with an individual's character. Compassion stems from virtue. It is a characteristic of the intent and practised disposition of the nurse and is affected by the culture and ethos of clinical practice (Bradshaw, 2011).

Compassion is emphasised to improve palliative care and should be seen as an essential aspect of high-quality palliative care (Brito-Pons & Librada-Flores, 2018). A review of compassionate care by Strauss et al. (2016) highlights five elements of compassionate care: 1) recognising suffering, 2) understanding the universality of suffering in human experience, 3) feeling empathy for the person suffering and connecting with the distress, 4) tolerating uncomfortable feelings in response to the person suffering, and 5) feeling motivated to alleviate suffering.

In this thesis, we have chosen a broad understanding of compassion as involving awareness of, or sensitivity to, the pain or suffering of others that results in taking verbal, nonverbal, or physical action to remove, reduce, or alleviate the impact of such affliction (Crawford et al., 2014; Gilbert, 2013). We have chosen this understanding of compassion because it includes intentions and actions regarding patients' and family caregivers' fundamental needs. Crawford et al. (2014) argue that compassionate care should include not only compassionate qualities of individual care but also the overall design of the health care system as a whole. The theoretical concept of compassionate care is clarified more completely in Chapter 3.

The thesis

The thesis consists of three studies. Family caregivers, nurses from primary care, and physicians from specialist health services and primary care were interviewed about care and participation in the various phases of the palliative pathway. Several theoretical frameworks have been applied in the studies. In Studies I and III, we found Thompson's theoretical framework valuable for elucidating the participation of family caregivers and patients in various phases of the palliative pathway. The four biomedical principles were as well used in Study III. When we started working with the transcript of the interviews with nurses, we found that the nurses primarily talked about care; consequently, we identified compassionate care as an appropriate framework for these analyses. We considered that using the concept of compassionate care in Study II would provide new and valuable knowledge about compassionate care in the palliative pathway. Moreover, we considered that these concepts could complement each other and provide a richer understanding of how patient participation and care were implemented in practice. The interrelation of the theoretical perspectives is elaborated further in Chapter 3.

In addition to the three articles this thesis consists of eight chapters. Chapter 1 is an introduction presenting the aim of the overarching thesis, the context of the studies, and the main theoretical concepts. Chapter 2 introduces the background. First, the position within palliative care is accounted for. Then the state of the art for the phenomena studied is presented. Chapter 3 presents the theoretical concepts and how they are interrelated, and Chapter 4 the purpose and aims. Chapter 5 presents the methodology, and Chapter 6 reports the findings. Chapter 7 discusses the findings, methodological choices and limitations. Finally, Chapter 8 presents the conclusion and explores implications for practice and suggestions for future research.

2 Background

Patient participation, family involvement, and compassionate care are complex matters within the context of palliative care This chapter provides the context for the study and offers an overview of existing research. Firstly, I present palliative care and palliative cancer care within the Norwegian context. Secondly, I present the state of the art concerning family involvement in cancer care, compassionate care from the nurse's perspective, and participation and involvement from the physician's perspective. Finally, I will present the summary and rationale for the thesis.

2.1 Palliative care

Palliative care is associated with improved quality of life and end-of-life care (Finn et al., 2017; Hui et al., 2018; World Health Organization, 2009). As stated in the introduction, the WHO defines palliative care as 'an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual' (World Health Organization, 2020). It is noteworthy to mention that the WHO's definition of palliative care is built on Cicely Saunders' principles of palliative care (O'Neill & Fallon, 1997). Cicely Saunders is one of the most significant contributors to the palliative care field. She introduced the concept of 'total pain', which means understanding patients' different needs during life-threatening diseases (Kaasa et al., 2016; Saunders, 2000; Strømskag, 2012). The principles of palliative care and the WHO`s definition of it apply to all chronic, life-threatening conditions, including heart failure, COPD, and neurological conditions, and to children as well as adults. The scope of this thesis, however, is limited to adult cancer patients in the palliative pathway.

Kaasa et al. (2018) in *Lancet Oncology* highlight six main elements of palliative cancer care: 1) respect for the patient's values, preferences, and expressed needs; 2) coordination and integration of care; 3) information, communication, and education; 4) physical comfort and relief of bothersome symptoms; 5) emotional support and relief of fear and anxiety, and 6) involvement of family and friends. These six goals integrate elements of oncology and palliative care. Kaasa et al. (2018) also highlight the importance of dialogue between two paradigms in oncology and palliative care: the tumour-directed approach and the host-directed approach.

Existing research reveals deficiencies in palliative care provision (McEwen et al., 2018; Røen et al., 2018). Though treatment for several types of cancer has improved; reducing the symptom burden and increasing survival rates, a significant number of patients develop advanced disease and need palliative care (Bray et al., 2021; Ferlay et al., 2021; Sung et al., 2021; World Health Organization, 2020), and patients in palliative care often have a high symptom burden (Laugsand et al., 2009; Teunissen et al., 2007). Therefore, introducing palliative care early in the disease trajectory is useful as a preventive measure to potentially prevent symptom crises and avoid treatments not in line with patient preferences, unnecessary hospitalisations, and information gaps (Finn et al., 2017; Hui et al., 2018; Kaasa et al., 2018; Verkissen et al., 2019). Hui et al. (2018) highlight the role of this early palliative introduction in patient education, proper symptom management, longitudinal counselling, spiritual care, understanding of the illness, and advanced care planning (ACP). Moreover, a review study found that although ACP could create unpleasant feelings for patients, many patients reported benefits from the use of ACP. Still, there is a need to tailor the process to the individual patient (Zwakman et al., 2018).

European patients receiving palliative care value autonomy, dignity, their relationship with healthcare professionals, quality of life, the position towards life and death, open communication, public education, multi-professional and interdisciplinary approaches, and grief and bereavement counselling (European Association for Palliative Care, 2008). Healthcare authorities increasingly emphasise that patients should have the opportunity to receive home-based palliative care (NOU 2017:16, 2017; World Health Organization, 2020). In addition, research has found that most people prefer to die at home (Fereidouni et al., 2021; Gomes et al., 2012; Tanuseputro et al., 2018), and those who receive formal care at home from healthcare personnel are more likely to do so (Danielsen et al., 2018; McEwen et al., 2018).

In one study from Canada, physicians identified the main factors promoting a home death to be patient characteristics, the physical environment, and support networks. Stability within these factors was essential (Wales et al., 2018). Moreover, home-based palliative care is associated with better symptom control and improved quality of life (Rabow et al., 2013).

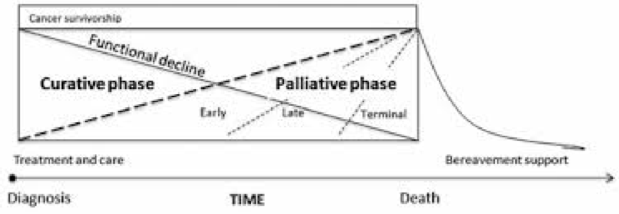
Nonetheless, home-based palliative care demands healthcare personnel experienced and competent in this area (Hov et al., 2020) and the support for family caregivers (Parmar et al., 2020; Pottle et al., 2017; Reigada et al., 2015). Today we have better treatments, which means that more patients will live in the palliative phase for an extended period of time (Bray et al., 2021; Ferlay et al., 2021; Sung et al., 2021; World Health Organization, 2020).

2.1.1 A model of phases in the cancer trajectory

Traditionally, cancer care has been divided into curative and non-curative pathways, with tumour-directed treatment being followed by a palliative course and possibly end-of-life care. Today, the need is being recognised for an integrated pathway; one in which palliative thinking occurs earlier while patients are still receiving non-curative tumour-directed treatment (i.e. palliative chemotherapy and biological treatment), and sometimes even in the curative pathway, because it is seen that the palliative approach is beneficial for reducing symptom burden and improving quality of life. However, the integration of palliative care in oncology is not equally well implemented everywhere (Kaasa et al., 2018).

We have in this thesis chosen an approach to cover the different phases in the palliative cancer care pathway with their various challenges. From the perspective of Thompson (Thompson et al., 2007; Thompson, 2007) and Beauchamp and Childress (Beauchamp & Childress, 2019), participation and involvement changes with the context. Against this background and in light of the research questions, it was essential to divide the palliative pathway into different phases. We were inspired by Grov's model (2014) of palliative cancer care (Figure 1) which identifies three phases in the treatment trajectory (Kaasa, 2008; Oken et al., 1982; Twycross, 2003).

Figure 1



The figure is retrieved from Grov (2014), Figure 1 on page 46, 'The cancer trajectory – a model of phases'. The figure is reproduced with permission from Rights link by Copyright Clearance Center with licence date Nov 05, 2021.

Inspired by Grov`s model, we divided the palliative pathway into three different phases: the first phase comprises the initial days following the diagnosis of an incurable disease, the middle phase constitutes the time between the early phase and the terminal phase, and the terminal phase comprises the last weeks and days before death and bereavement support after the death. Based on my work as an oncologic nurse in community palliative cancer care, Grov`s model seemed appropriate. The model also fits well with the research questions and contextuality of the palliative pathway. We used Grov's model in our interview guide to bring out the context of the phenomena we studied. The model was also helpful in coding data within the different phases in the three studies.

2.1.2 Palliative care in a Norwegian context

This research project is carried out in a Norwegian context. Norwegian health policy defines a goal of offering palliative care at home, a goal that has evolved in recent decades (Helse- og omsorgsdepartementet, 2009, 2013, 2020; NOU 2017:16, 2017; World Health Organization, 2020). Furthermore, the coordination reform in Norway has led to a significant shift of tasks from specialist health services to primary care health services (Hagen et al., 1997; Helse- og omsorgsdepartementet, 2009, 2015a; Sogstad et al., 2020; Vabo & Vabø, 2014). This transfer of tasks aligns with the WHO's idea that palliative care should be integrated into primary care (World Health Organization, 2018a). The coordination reform was initiated by the central government and implemented in 2012, and included various instruments of governance. In addition, economic incentives were applied to encourage the municipalities to take greater responsibility for healthcare services (Helse- og omsorgsdepartementet, 2009). In 2020, 10,981 people in Norway died of cancer (Cancer Registry of Norway, 2021). Norway is one of the countries in the world with the lowest number of home deaths (Helse- og omsorgsdepartementet, 2009, 2015a, 2020; NOU 2017:16, 2017).

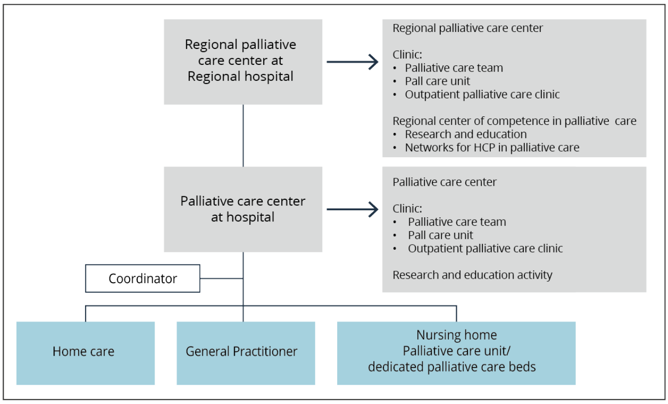
Norwegian health policy documents focusing on allowing more time at home and promoting home death, this will have consequences for family caregivers. Concurrently, the Health and Care 21 (HelseogOmsorg21) strategy pointed out that the increase in tasks would be more significant than the increase in resources (Helse- og omsorgsdepartementet, 2014). Family caregivers are seen as essential contributors to the patient's care (Helsedirektoratet, 2017; NOU 2017:16, 2017). These caregivers might experience a more stressful everyday life than the patients themselves, and feel unsupported (Helse- og omsorgsdepartementet, 1999). Family caregivers involved in the care of the patient are given information about the patient's condition only if the patient consents to such information being given. When consent is given, they do, as a rule, have information about the patient's health condition, including diagnosis and treatment prospects and health care. However, the patient can decide that family caregivers should be provided only limited and specific information (Helse- og omsorgsdepartementet, 1999). Still, in political documents, healthcare personnel are encouraged to involve family caregivers in decision-making and care (NOU 2017:16, 2017).

The follow-up and treatment responsibility of the municipalities has thus increased in recent decades. However, there is no generalised service model in the municipalities regarding palliative care, the service models differ between generalist and specialised palliative care models. Furthermore, larger municipalities offer more specialised care services than smaller municipalities (Sogstad et al., 2020).

Palliative care in Norway is divided into primary and specialist palliative care (Figure 2). In primary care, the municipalities are responsible for follow-up and care. The specialist service is organised through hospital trusts by the Norwegian government. Although the follow-up differs in primary and specialist care, the two services often work side-by-side (Helsedirektoratet, 2019). Working together to provide seamless care is crucial for the palliative teams, home-care services, GPs, cancer coordinators, and nursing homes.

Figure 2

Regional palliative care center at the regional hospital



Translated into English from NOU 2017:16-regjeringen.no

There are 356 municipalities in Norway responsible for primary health care services, home care, social care, and long-term care (Saunes et al., 2020). Primary care differs between these municipalities. For example, some areas have community palliative teams while others have cancer coordinators; some have both, and some have none of these structures. Every patient is intended to have general practitioner, and some municipalities offer palliative units or palliative beds in nursing homes. There are two kinds of units in specialised palliative care: the palliative hospital ward and the palliative care teams, which cooperate with the primary carers to deliver palliative treatment to patients in their homes or nursing homes (Helse- og omsorgsdepartementet, 2020; Johansen & Ervik, 2018).

In the specialist health service, palliative care is provided in ordinary hospital wards and specialised palliative care units with palliative care teams, outpatient clinics, or pain clinics (Helse- og omsorgsdepartementet, 2020). Palliative care teams are an integral part of the philosophy of palliative care and offer benefits to patients, practitioners, and primary carers (Crawford & Price, 2003). Palliative care teams provide broad expertise within multidimensional care for patients and family caregivers. This expertise leads to better symptom control, improved quality of life for patients and family caregivers, and better end-of-life care, complementing primary palliative care (Helse- og omsorgsdepartementet, 2020; Hui et al., 2018). Interdisciplinary teams within palliative care are seen as central and unique (Ahluwalia et al., 2018; Sun et al., 2015). Promoting optimal palliative care depends on close collaboration and dialogue between patients, family caregivers, home care services, and GPs (Danielsen et al., 2018). However, hospital outpatient clinics within oncology strive to transfer palliative cancer patients early in the pathway to the municipalities to ensure competence in the last phase at home (Brenne et al., 2020).

Home-care service is a vital part of palliative care, and its aim is to reduce unwanted and unnecessary hospitalisations (Munkejord et al., 2018). Nurses, other healthcare workers, and assistants are directly involved in palliative care at home with patients and their families. Some municipalities have employees, such as oncological and palliative nurses, who hold an expert role (Helse- og omsorgsdepartementet, 2020; Lie et al., 2018). The home-care service works closely with the GP, cancer coordinator, nursing homes, and palliative care service.

In Norway, there is universal access to public health care, and the GP has a vital role in the follow-up of patients living at home as she or he is, with few exceptions, given the medical responsibility for such patients (Oosterveld-Vlug et al., 2019). Moreover, the GP often possesses background information and has developed a relationship with the patient and the family over time (Helse- og omsorgsdepartementet, 2020). However, there is evidence that GPs in rural communities and small towns contribute more to palliative care than those in urban areas (Holtedahl et al., 2018; Meiklejohn et al., 2016). Some municipalities have cancer coordinators (CCs), which are typically specialist cancer nurses working with cancer patients in palliative care (Lie et al., 2018). Some CCs work at a system level, while others work closer to the patients and families (Melby et al., 2017). These CCs help to strengthen cancer care for patients in the last phase of life (Helse- og omsorgsdepartementet, 2020), providing coordinating care for patients and family caregivers (Lie et al., 2018).

Many municipalities have a palliative care unit which is an option for patients who do not have the opportunity to receive care in their own homes or who need additional help with symptom control. These units provide services to patients with a greater or more complex need for palliative care and nursing than what ordinary long-term or short-term wards offer. The associated physicians are responsible for the medical treatment, but specialist palliative teams support the physicians and nurses in their work (Helse- og omsorgsdepartementet, 2020).

2.2 Previous research

In this section, I present existing research on family involvement, compassionate care, and patient participation that is relevant to the purpose of the thesis. Before the start of the project, a literature review was conducted, and with the help of a librarian I conducted several systematic literature reviews between January 2017 and May 2022.

2.2.1 Family involvement in palliative care

Previous research has shown that family caregivers are crucial in arranging home-based palliative care, including organising the care tasks themselves and making arrangements for the patient to die at home. The role of family caregivers can further include being responsible for the continuity of care and making decisions at the end of life (Danielsen et al., 2018; Hov et al., 2020; Kjellstadli et al., 2018; Knighting et al., 2016; Reigada et al., 2015; Woodman et al., 2016). That healthcare personnel have a holistic focus on the patient is essential to family caregivers’ satisfaction, as is quality of care (De Boer et al., 2017; Ringdal & André, 2014).

To be given the opportunity to care for the patient at home might feel like a reward for family caregivers (Henriksson et al., 2015; Hudson, 2004). There is, however, a complexity to balancing the demands of caring for someone dying at home with the satisfaction such efforts might yield, and that balance depends on whether family caregivers perceive the home setting as the best place for the patient to die (Pottle et al., 2017). Patients already living at home with family caregivers was associated with more planned home care and home deaths (Kjellstadli et al., 2018). A study from Wales found that patients are able to maintain a certain degree of normality during time spent at home, while their family caregivers experience the opposite, and in these circumstances the patient’s needs and wishes became more important than those of the family caregivers (Pottle et al., 2017).

Family caregivers are key persons in palliative care when the patient stays at home (Brogaard et al., 2011), and it seems complicated to balance the burden of care with their ability to cope (Andershed, 2006; Funk et al., 2010; Knighting et al., 2015; Proot et al., 2003; Stajduhar et al., 2010). Studies from Europe on the burden experienced and the balance of burden and vulnerability have found that family caregivers can feel overwhelmed by the burden of making decisions they may not fully understand the consequences of (Proot et al., 2003; Rakic et al., 2018). This burden could be a barrier to family caregivers' satisfaction with palliative care at home. Other causes of dissatisfaction for family members include lack of information regarding the prognosis, unsatisfactory family conferences with medical professionals, and lack of involvement of family caregivers in care decisions (Naoki et al., 2018). The burden of the patient’s illness and of providing care affects family caregivers emotionally, physically, socially, and financially (Funk et al., 2010; McDonald et al., 2018; Stajduhar et al., 2010; Veloso & Tripodoro, 2016; Virdun et al., 2015; Virdun et al., 2017).

Research has found that family caregivers are essential in the decision-making process, and that patients often deliver their final decisions only after having consulted with the family (Dionne-Odom et al., 2019; Gray et al., 2019; Lamore et al., 2017). Family caregivers involved in decisions tend to handle the home-care situation better, while family caregivers who are less involved in decisions or uninformed, are more likely to feel unprepared for the role and often neglect their own needs (Stajduhar & Davies, 2005). Family caregivers may desire more information about the dying process and the period following death, while patients may focus more on being pain-free and maintaining dignity, not wanting to discuss dying in depth (Watts, 2012). A review from 2017 found that family caregivers’ involvement varies according to illness, treatment choice, culture, and family-related factors. Nonetheless, family caregivers' influence on the decision-making process informing treatment is rarely described (Lamore et al., 2017). Family caregivers heavily involved in the patients decision-making could be meet with suspicious, family caregivers could counter the patients autonomy (Ho, 2008).

A personal relationship with the health professional and transparency in communication are found to be particularly important (den Herder-van der Eerden et al., 2017; Dose et al., 2015; Røen et al., 2018). Further, the importance of being fully informed about the condition of the patient and what to expect is highlighted in existing research (Knighting et al., 2015). This emphasis is supported in a recent review from 2022 about factors that help to increase quality of life for family caregivers. These factors were related to the ability of professional care teams to communicate information about the disease, treatment, and side effects and especially to the participation of family caregivers. It was essential to family caregivers' quality of life that they were involved in planning and treatment decisions, had emotional and social support, was enabled to master the relevant care practices, and received clear communication about the diagnoses (Pop et al., 2022). A review by Wang et al. (2018) found that information on illness, treatment, and care was lacking. Family caregivers often receive insufficient support from healthcare personnel (Aoun et al., 2015; Bee et al., 2009). Research indicates wide variation in the delivery of bereavement conversations and in the relevant resources used (Ahluwalia et al., 2018; Johnson, 2015; Kutner & Kilbourn, 2009).

A focus on family caregivers' involvement and their needs is warranted (Lund et al., 2015). However, there is a gap between the emotional and psychological support needed by family caregivers and the guidelines of palliative care (Aoun et al., 2017). As a result, family caregivers experience deficiencies (McEwen et al., 2018; Røen et al., 2018). One systematic review found a lack of practical support and skills training, and the communication between family carers and healthcare personnel was found to be poor (Bee et al., 2009). An essential factor for strengthening family caregivers' approach to palliative care is information about the illness, the palliative care available, the prognosis, and the death itself (Røen et al., 2018). Another review of family caregivers' preferences and perspectives found that family caregivers need support from health professionals and emphasised that they should not feel pressure to provide palliative care at home (Woodman et al., 2016).

Tools to support family caregivers have been recommended (Kaasa et al., 2018; Stajduhar et al., 2010). The Carer Support Needs Assessment Tool (CSNAT) developed for family caregivers in palliative care identifies the family carers' needs and provides guidance about how to be self-supportive, and how the family carer might support the patient (Aoun et al., 2015; Ewing et al., 2013; Ewing & Grande, 2013). According to the research of Aoun et al. (2015), the use of CSNAT resulted in family caregivers that experienced less strain, had greater access to support (Aoun et al., 2015), and were more likely to have their needs identified by nurses (Aoun et al., 2015). In addition, the research of Grande et al. (Grande et al., 2017) found that the use of the CSNAT might support the grieving process, leading to better psychological and physical health.

2.2.2 Compassionate care from the nurse's perspective

According to a review by Sinclair et al. (Sinclair et al., 2016), there are two conditions for compassion in a relationship: there must be a person who is suffering and a person who desires to relieve the suffering. The review shows that compassion consists of specific skills like acknowledging, responding to, understanding, and actively addressing the suffering of another. Moreover, clinicians' qualities of compassion are actualised through acknowledgement, engagement, and action when a patient is suffering. Research from New Zealand presents a bi-cultural approach to providing compassionate end-of-life care (Robinson et al., 2019). The Kapakapa Manawa framework was developed by drawing on empirical research that captured the experiences of palliative care in hospitals from the perspectives of bereaved families (Dewar & Nolan, 2013; Durie, 1985; Gott et al., 2019). The researchers have extended the framework to encompass Māori values of compassion during end-of-life care.

The Kapakapa Manawa framework differs from others by noting how compassion should be integrated into nursing practice by referring explicitly to compassion as an action. The model considers patients' cultural background in care provision and the family members involved (Robinson et al., 2019). Knowing enough about patients and developing trust is an important element in this framework. Conceptualising compassion as an action may be used as a platform on which to develop meaningful relationships (Robinson et al., 2019). This framework outlines four values that optimise compassionate nursing in the palliative pathway: 1) the cultivation of relationships that express care, 2) the process of establishing good relationships, 3) the use of contextualised knowledge, and 4) a reciprocal process of mutual respect between people. The Māori concept relates to establishing relationships and nurturing ongoing connections through practical inter-relational caring (Robinson et al., 2019).

According to Larkin (2016), is compassion the essence of palliative and end-of-life care. That genuine compassion is expressed through the highest level of clinical practice, which addresses the totality of symptom burden and complex needs. Compassion implies a sense of coherence, where the nurses are able to communicate compassion based on knowledge, proactivity, and interconnectedness in the delivery of nursing. Compassion is a matter not just of individual responses but also of how the system enables nurses to sustain and support themselves in the complexity of palliative care (Larkin, 2016). Moreover, compassion creates an environment of safety and is built on trust and good relationships among the patient, the family, and the healthcare personnel (Brito-Pons & Librada-Flores, 2018; Larkin, 2016).

A review by Brito-Pons and Librada-Flores (2018) found, first, that compassion is understood as acknowledging a person's suffering and feeling motivated to help them and, second, that compassionate care by nurses is a matter of values, attitudes, and behaviours. Nurses can, in addition, play a key role in integrating palliative care and oncology by providing compassionate care (Brito-Pons & Librada-Flores, 2018).

A study that included participants from 15 countries explored nurses' understanding of compassion (Papadopoulos et al., 2017). In this study, the nurses reported a lack of time to be an obstacle to the provision of compassionate care and highlighted the importance of politics in shaping the perception of compassionate care and enabling nurses to practice with compassion. It was found that socio-political structures constrained and influenced their care provision.

Nurses have a coordinating role between patients, families, and other health professionals in palliative care which can be challenging (Sekse et al., 2018). Wilson et al. (2014) report that primary care nurses have noted that family dynamics impact complex and challenging situations. The family, the patient, and the nurses may all be at different stages in accepting death. Furthermore, conflict may arise when patients conceal information or misunderstand what is being communicated to them and feel suspicious (Lund et al., 2015; Wilson et al., 2014).

A study from Canada by McEwen et al. (2018) found that patient and family-centred care promotes compassionate care and that empathy, respect, and partnership are overarching values. Communication, shared decision-making, and goal setting are seen as necessary for promoting compassionate care in the palliative setting. Furthermore, palliative care patients' advice to nurses is to communicate effectively, show interest, and respect patients facing the end of their lives. Receiving formal care at home is a predictor of dying at home (McEwen et al., 2018). Compassion concerning end-of-life care is structured around patients and family caregivers and emphasises values such as empathy, sharing, respect, and partnership (Pfaff & Markaki, 2017).

Research on home-care nurses in Canada has pointed out that building trust and knowledge is valuable during end-of-life care, but that this process of building trust depends on nurses' availability (Stajduhar et al., 2011). Compassionate care facilitation includes personal and relational characteristics, the organisational framework, and an individually tailored care system. Research has identified some key elements necessary for community nurses to support the patient in dying: symptom control, promoting patient choice, honesty, spirituality, interprofessional relationships, organisation of care, and seamless care (Griggs, 2010). The identified barriers to compassion include personal challenges, relational challenges, system challenges, and maladaptive responses (Singh et al., 2018).

A Norwegian study (Devik et al., 2020) that explored nurses' experiences with compassion when caring for palliative patients through in-home nursing, found that nurses experienced both the presence and absence of compassion when caring for palliative patients at home. Three themes emerged from the nurses' experiences of compassion in this setting: perceiving the patient's plea, interpreting feelings, and reasoning about accountability and action. The conclusion drawn in the study was that the experience of compassion seems to be influenced by variations in awareness, attention, and engagement situated in caring interactions characterised as positive, negative, or neutral (Devik et al., 2020).

The need for more compassionate care is emphasised, but the literature on nurses in practice is sparse (Blomberg et al., 2016; Feo et al., 2018). Reviews by Blomberg et al. (2016) and Feo et al. (2018) show that little is said to front-line practitioners about how to practice compassionate care, especially in contexts where the need for greater compassion is needed.

The focus in the literature on compassion seems to be on moral attributes, especially in nursing care (Blomberg et al., 2016; Feo et al., 2018). Feo et al. describe this need for nurses to demonstrate values, behaviours, and attitudes and to establish meaningful and respectful relationships with the patient and the family caregivers. Papadopoulos et al. (2017) surveyed more than one thousand nurses from 15 countries on their perceptions of compassion and identified five components comprised in compassion: 1) investing time in the patient–nurse relationship, 2) presence, 3) going the extra mile, 4) personalisation, and 5) advocacy. I consider these components as crucial in palliative care.

2.2.4 Physicians' perspective on patient participation and family involvement

Physicians play an essential role in patient participation and family involvement in palliative care, and research has shown that understanding patients' preferences and needs for palliative care must start with the healthcare professionals (Ebenau et al., 2017; Ringdal et al., 2017; Sandsdalen et al., 2015). Healthcare personnel's behaviour, attitudes, and beliefs affect patient participation (Longtin et al., 2010).

A review found that navigating difficult conversations was viewed as challenging for physicians. The physicians' recommendations in communication where in this regard focused on patient-centred communication guided by ethical principles, legal precedence, and emerging evidence regarding patients' preferences (Johnston & Beckman, 2019).

An earlier study and a reviews found that physicians faced barriers with end-of-life discussions, including prognostic uncertainty, fear of causing distress, navigating patient readiness, and feeling unprepared for these conversations (Back et al., 2008; Brighton & Bristowe, 2016; Kennedy et al., 2014). Nevertheless, Brighton and Bristow highlight that the opportunity to have these conversations aligned with patients' and family caregivers' preferences (Brighton & Bristowe, 2016). Barriers and facilitators in promoting better and safer care often depend on physicians' perceived time available, organisational support, and the individual physicians and patients involved (Fine et al., 2010; Schildmeijer et al., 2018). Schildmeijer et al. (2018) have mapped these barriers and facilitators into five categories: 1) physicians' capability to involve patients in their care; 2) patients' capability of becoming involved in their care as perceived by physicians; 3) physicians' opportunity to achieve patient participation in their care; 4) physicians' motivation to involve patients in their care; and 5) patients' motivation to become involved in their care as perceived by physicians.

Most clinicians want to involve the patients in their care; however, they may not know how to present options and introduce shared decisions, and their behaviour could either promote or hinder patient participation in the decision-making process (Bélanger et al., 2016; Schildmeijer et al., 2018). A literature review by Marcus and Mott (2014) showed that communication training in delivering bad news and discussing end-of-life treatment was lacking, and that many physicians struggled with these difficult conversations. This struggle could lead them to avoid delivering bad news and initiating discussions of end-of-life treatment. Supporting healthcare personnel in palliative care and end-of-life communication is a key task (Brighton & Bristowe, 2016). Physicians need to prepare their advanced cancer patients and their families for the emotions they will likely experience in the grieving process (Kutner & Kilbourn, 2009). Moreover, early discussion with patients about care goals in the context of serious illness is a key to improve end-of-life outcomes (Bernacki & Block, 2014).

To receive psychological follow-up, especially late in the palliative pathway, is essential for patients and family caregivers. Another important task for the physicians is liaising between patients and healthcare personnel in primary and specialist care (Holtedahl et al., 2018; Meiklejohn et al., 2016). In addition, one of the critical factors that may predict home death among palliative care patients, is the availability of home visits by their physicians (Driller et al., 2022; Ko et al., 2017; Tanuseputro et al., 2018).

Physicians’ support of and involvement with family caregivers could improve family caregivers’ health and satisfaction with the process (Parmar et al., 2020). In their review of physicians’ perspectives on their role in supporting family caregivers, Parmar et al. found that physicians acknowledge that family caregivers benefit from contact with the primary care team, caregiver coordinator, and community support. Nonetheless, physicians’ roles in caregiver-centredness are not well defined and vary widely. Parmar et al. also found that family caregivers seldom ask for support and that there is an expectation that physicians should refer patients and family caregivers to the appropriate support and health services (Parmar et al., 2020).

2.2.5 Summary of previous research and the rationale of this thesis

Research has shown that family caregivers experience challenges and a lack of information and involvement in the palliative care pathway. Family caregivers are crucial for arranging palliative care at home, and this might cause a complicated balance between the feeling of being burdened and the ability to cope, and between satisfaction and demands. It is essential for family caregivers to be supported by health personnel and not to feel pressured to take on palliative care at home. It is important that they are involved in planning and treatment decisions, receive emotional and social support, have opportunities to master the care skills required, and are engaged in effective communication about the diagnoses. Family caregivers appear to be essential in patients' decision-making processes, but their influence on shared decisions are rarely described. Personal relationships with health personnel, transparency, and the use of tools like the CSNAT might reveal the areas in which they need support. With the use of the CSNAT, family caregivers experienced less strain, had greater access to support, and felt their needs were recognised by the nurses.

Nurses are responsible for care, administration of treatment, and providing information to the patient and family caregivers. Patient- and family-centred care promotes compassionate care, and empathy, respect, and partnership are overarching values.

Components comprised in compassion include investing time in the patient–nurse relationship, presence, going the extra mile, personalisation, and advocacy. These components create an environment of safety that is built on trust and good relationships. Compassion involves specific skills like acknowledging, responding to, understanding, and actively addressing the suffering of another. Moreover, qualities of compassion are actualised through acknowledgement, engagement, awareness, attention, and action. Compassion is an important element of the highest level of clinical practice, which addresses the totality of symptom burden and complex needs. Compassionate care thus can promote patient participation and the involvement of family caregivers.

Physicians play an essential role in patient participation and family involvement and are responsible for treatment choices. Physicians are viewed as key links between patients and healthcare personnel in primary and specialist care. Early discussion with patients about care goals in the context of serious illness improves end-of-life outcomes, but many physicians struggle with these difficult conversations. Physicians want to involve patients in their care, but it can be challenging to promote shared decisions and navigate difficult conversations. Discussions about care goals and the involvement of family caregivers are highlighted as important issues by physicians. To be followed up by physicians seems essential for patients and family caregivers and is a predictor for home death.

Patient participation, family involvement, and compassionate care are contextual (Brito-Pons & Librada-Flores, 2018; Griggs, 2010; Lund et al., 2015; Robinson et al., 2019; Røen, 2022; Singh et al., 2018; Thompson et al., 2007; Thompson, 2007; Wilson et al., 2014), and therefore it is essential to study these concepts as they relate to different phases in the cancer care pathway, given that the experiences of patients, family caregivers and healthcare personnel might differ across phases.

Earlier research has found that healthcare personnel and family caregivers might have different experiences of the different phases of the pathway. The review of the literature reveals knowledge of and interest in patient participation, family involvement, and compassionate care; however, little is known about how these pertain to the different phases of the palliative cancer care pathway. Given this background, there is a need for studies that focus on family caregivers' and health professionals' experiences and perceptions of patient participation, family involvement, and compassionate care in the different phases of palliative care.

The aim of the present thesis thus was to obtain knowledge about patient participation, family involvement, and compassionate care as experienced by family caregivers and health personnel in the different phases of the palliative cancer care pathway.

3 Theoretical frameworks

In this thesis, I explore patient participation, family involvement, and compassionate care in the various phases of the palliative pathway. I first introduce patient participation and family involvement; second, compassionate care; third, the four biomedical principles; and finally, how these various theoretical concepts are interrelated. Patient participation, family involvement and compassionate care are crucial in the palliative cancer pathway (Bélanger et al., 2016; Kaasa et al., 2018; Larkin, 2016; Schram et al., 2017; Wakefield et al., 2018).

In each of the three studies, we have used a particular theoretical framework as a lens or perspective when conducting the qualitative research (Malterud, 2017). The theoretical framework has guided our research toward the important issues under study. According to Creswell (2014), the theoretical framework indicates the researchers' position within the study. Theoretical frameworks are important in qualitative studies, representing the best effort to describe and explain a phenomenon and serving as a springboard for knowledge in practice (Polit & Beck, 2012). We have used the theoretical perspectives to bridge description and interpretation (Malterud, 2017).

The studies use different theoretical perspectives: Patient participation and involvement (Thompson et al., 2007; Thompson, 2007), compassionate care (Bradshaw, 2011; Kanov et al., 2004; Strauss et al., 2016), and the four biomedical ethical principles (Beauchamp & Childress, 2019). These theoretical approaches have different historical and etymological roots. However, they also have common features that relate to the quality of care in the palliative pathway. In Chapter 3.1, I explain the theoretical perspectives adopted in this thesis and their interrelations, clarifying the common features between them, their differences, and how they provide a complementary understanding of participation and quality in palliative cancer care.

3.1 Patient participation and family involvement

n the literature, several related concepts are described, such as patient-centred care, patient education, empowerment, engagement, involvement, activation, and partnership (Castro et al., 2016). Based on 13 prior published definitions, Castro et al. (2016) propose a definition of patient participation: 'Individual patient participation revolves around a patient's rights and opportunities to influence and engage in the decision-making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professionals' expert knowledge' (p. 1929). Castro et al. (2016) highlight patient participation as a strategy for achieving patient-centred care, arguing that a patient-centred approach leads to patient empowerment. They propose the following definition of patient-centredness: 'Patient centeredness is a biopsychosocial approach and attitude that aims to deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy, and shared knowledge.' In addition, patients should participate in decisions about their healthcare (Brighton & Bristowe, 2016; Vahdat et al., 2014; World Health Organization, 2020) because participation is a core element of patient-centred care within the palliative context (Bélanger et al., 2011; Kaasa et al., 2018). Patients can be involved in different ways, such as in reaching a diagnosis, choosing treatment, treating side effects, and self-care management; such involvement might change patients' outcomes via service delivery (Ocloo & Matthews, 2016).

Cahill (1996) established five preconditions to achieve participation: 1) a relationship must exist; 2) there must be a narrowing of the appropriate information, knowledge, or competence gap between nurses and patients using suitable modalities in different contexts; 3) the nurse must surrender a degree of power or control; 4) there must be engagement in selective intellectual and/or physical activities during some phases of the healthcare process; and 5) there must be a positive benefit associated with the intellectual and/or physical activity (Cahill, 1996).

In a review Angel and Fredriksen (2015) identified challenges towards achieving patient participation in the relationship between patients and nurses. They found that a strong relationship, the patient feeling acknowledged, and effective exchanges of information were necessary to facilitate participation. Further, nurses' knowledge, attitudes, and available time affected participation. These components are interrelated and require time and cooperation. Angel and Fredriksen (2015) find that although ideal patient participation is not achievable, a high level of participation can be achieved through building relationships and sharing knowledge.

Patients' participation can be divided into micro-level, meso-level, and macro-level involvements. Micro-level involvement relates to the relationship between healthcare personnel and patients. The meso-level is the organisation of healthcare services, and the macro-level includes society and governing authorities (Halabi et al., 2020; Olsson et al., 2020). Though our studies focus on the micro-level, the findings may have implications for the meso- and macro-levels as well.

We have chosen to use Thompson's theoretical perspective of participation (Thompson et al., 2007; Thompson, 2007), which is appropriate to study clinical situations. In Thompson’s view, patient participation occurs at the level of shared decision-making and dialogue and can only be achieved through two-way communication between patients and healthcare personnel. In Study I, we use Thompson’s (Thompson, 2007) taxonomy of involvement and Thompson et al.’s (2007) integrative approach to patient involvement and participation. We wanted family caregivers’ views of involvement and information. According to Thompson, involvement is more relevant and important in chronic conditions than acute illness. To establish involvement, one must establish a mutual relationship and dialogue. Participation must be based on respect, dialogue, and an open relationship. Further, a high degree of involvement yields greater responsibility. Thompson’s framework is based on three core elements: components, context, and levels (Thompson et al., 2007; Thompson, 2007).

The *components* of participation and involvement (Figure 3) consist of the following: 1) the patient contributes to the direction of action, for example, through initiation or response; 2) the patient influences the definition of the problem; 3) the patient takes a role in the process of reasoning, discussing issues and possible solutions; 4) the patient influences decision-making; and 5) emotional reciprocity is experienced between patients and health personnel.

Figure 3

COMPONENT	LEVEL OF INVOLVEMENT				
	Non-involved 0	Information-seeking / receptive 1	Information-giving / Dialogue 2	Shared decision-making 3	Autonomous decision-making 4
Contribution to action sequences					
Influence in problem definition					
Share in reasoning process					
Influence in decision making					
Emotional reciprocity					

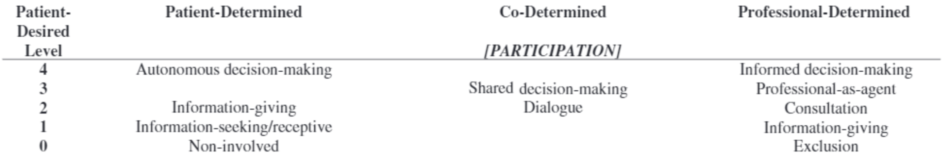
Matrix of interactions between components and levels of patient participation, with permission from Andrew Thompson, mail 04.11.22.

Within the *context*, the level of involvement can vary (Thompson et al., 2007). The most striking differences may be between acute and chronic illness. In acute settings, the patient experience of involvement is reduced (Andersen-Hollekim et al., 2019; Bårdsgjerde, 2022; Thompson et al., 2007).

The *levels* consist of five degrees of patient-desired involvement (Figure 3 and 4) (Thompson, 2007). Each level represents a different position of power, ranging from non-involvement to full autonomy. Thompson derives his taxonomy from patients' views of involvement and the level at which patients want to be involved. The taxonomy is broad and not related to diagnosis. Involvement depends upon the context and patients' preferences; however, patients may move between levels over time. Thompson describes a range of patient involvement from being excluded in decisions to shared decision-making—in other words, from a paternalistic approach to an equal dialogue (Thompson et al., 2007; Thompson, 2007).

From Thompson's taxonomy, we use the five *levels* of involvement (Figure 4), ranging from non-involvement to full autonomy, as a power scale. Level 0 represents non-involvement; reasons for non-involvement include patients' trust in healthcare professionals, patients' lack of medical knowledge, and deliberate avoidance of placing burdensome responsibility on the patient as a way of coping with their fear and anxiety. Level 1 refers to information-seeking or receptive involvement and is understood as an elementary stage of involvement. Understanding the illness or condition is a core requirement for this level; clear information is identified as an essential building block for decision-making. Level 2 represents information-giving or dialogue, which involves two-way communication; the patient is listened to and heard. At level 3, shared decision-making occurs. Shared decision-making implies that the patients' opinions are valued in decision-making. Finally, level 4 represents autonomous decision-making, observed primarily in patients with chronic illness. Patients make decisions based on their own experience of illness and knowledge of their condition. Following Thompson (Thompson, 2007), we have considered components, levels, and context when identifying themes.

Figure 4



Patient-Desired Level	**Patient-Determined**	**Co-Determined**	**Professional-Determined**
		[PARTICIPATION]	
4	Autonomous decision-making		Informed decision-making
3		Shared decision-making	Professional-as-agent
2	Information-giving	Dialogue	Consultation
1	Information-seeking/receptive		Information-giving
0	Non-involved		Exclusion

Fig. 2. Levels of involvement.

The figure is retrieved from Thompson (2007) Figure 2 on page 1306. ‘The meaning of patient involvement and participation in health care consultations: a taxonomy’. The figure is reproduced with permission from Elsevier with licence date Nov 07, 2021 and licence number: 5183650892719

Although Thompson's framework was developed to understand patient participation and involvement, components have been successfully applied to family caregivers, and it can provide a valuable framework for understanding family caregivers' involvement (Aasen et al., 2012). According to Thompson, his framework is intended to facilitate the identification of linkages and contributions to be made, across different research approaches and disciplines, in studies of patient participation.

In Study I, we analysed experiences with participation and involvement in the palliative pathway from the perspective of family caregivers. In Study III, we analysed physicians' perceptions of participation and involvement of patients and family caregivers in the palliative pathway. We saw Thompson’s (Thompson et al., 2007; Thompson, 2007) theoretical perspective as relevant within the palliative pathway. Participation is contextual, we explored this perspective in the different phases of the palliative pathway. Their theoretical framework has inspired analysis, and interpretation of the data.

3.2 Compassionate care

We chose compassionate care as one theoretical perspective because this concept is considered crucial in palliative care (Brito-Pons & Librada-Flores, 2018; Pfaff & Markaki, 2017). In our understanding, compassion consists of three dimensions: noticing, feeling, and responding (Kanov et al., 2004). In addition, we view compassion as a design feature of care and healthcare organisations (Crawford et al., 2014). Based on the literature and my clinical background, I conclude that compassionate care is an essential part of palliative care. We think that nurses can play an important role in integrating palliative care and oncology by providing compassionate care. Compassionate care includes many of the recommendations from the Lancet commission for patient and family caregivers (Kaasa et al., 2018). Compassionate care can be seen as an overarching approach integrating various aspects of care (Crawford et al., 2014).

There are various definitions of compassionate care (Crawford et al., 2014; Feo et al., 2018; Strauss et al., 2016). Many of these are general and do not consider the uniqueness of patients, contexts, and situations. I see compassionate care as a value base for good care regardless of different definitions.

3.3 The four biomedical ethical principles

In Study III, we chose the four biomedical ethical principles (Beauchamp & Childress, 2019) and Thompson's theory of involvement and participation (Thompson et al., 2007; Thompson, 2007) to explore physicians' perceptions of participation among patients and their family caregivers. Thompson's theoretical framework contains different levels and values. The physicians communicated a lot about ethical reasons and underlying their practice, and it became apparent that there was a need for ethical theory. It was valuable to supplement the perspectives of participation and involvement.

In biomedical ethics, the four principles of healthcare are: 1) autonomy—respecting the decision-making capacities of autonomous persons; 2) non-maleficence—avoiding the causation of harm; 3) beneficence—providing benefits and balancing benefits, burdens, and risks; and 4) justice—fairly distributing the benefits and risks.

Autonomy refers to respecting the decision-making capacity of autonomous persons and their right to participate and ensuring informed consent in important decisions. Therefore, the health legislation's provision on consent competence might be necessary to promote autonomy. Respectful treatment in disclosing information and actions fostering autonomous decision-making are required. This principle obliges those disclosing information to probe for and ensure understanding and voluntariness and to foster adequate decision-making (Beauchamp & Childress, 2019). *Non-maleficence* refers to avoiding the causation of harm and protecting against unnecessary harm. Assessment and treatment are burdensome and can involve a health risk. Therefore, the risk of injury should be less than the expected benefit of any examination, treatment, or other healthcare intervention. Moreover, one ought not to inflict evil or harm, where harm is understood as preventing, defeating, or setting back someone's interests (Beauchamp & Childress, 2019). *Beneficence* (Beauchamp & Childress, 2013) refers to providing benefits and balancing benefits, burdens, and risks. One ought to prevent and remove evil or harm. One ought to perform and promote good. In addition, beneficence balances the utility value and benefits of treatment choices against the risk and strain to which the person is exposed. Therefore, health personnel must behave in a way that benefits the individual's life and health-related quality of life. For example, a physician and a nurse have a duty to be of benefit to their patients, to do something good for them, precisely by virtue of being knowledgeable professionals. Hence, it is their duty to do good, or their duty of beneficence, that is fundamental, going beyond the duty not to harm (Tranøy, 2005). *Justice* refers to fairness in the distribution of benefits and risks. It is about the management and distribution of opportunities, health benefits, and resources. Costs and resources should be distributed in a fair way and managed with the intention of treating cases equally (Beauchamp & Childress, 2019).

According to Beauchamp and Childress, these four principles are not specific to biomedical ethics; they form the core of universal common morality. Furthermore, none of the principles is more worthy than another; in practice, they should be balanced.

Patients have the right to be told the truth, but in some conditions, physicians do not provide all the information all at once concerning their patients' medical circumstances. Communication of relevant information is essential to obtain informed consent, but the management of information in medical care goes beyond informed consent. Healthcare professionals should cautiously manage information and, in some circumstances, communicate information over time (Beauchamp & Childress, 2019).

3.4 How the theoretical perspectives are interrelated

The various theoretical perspectives were chosen to gain insight into patient participation, family involvement, and compassionate care in the palliative cancer care pathway. Using various theoretical perspectives might be seen as a logical weakness. In our view, it might be a strength that could give a more comprehensive understanding of patient participation, family involvement and care in the palliative pathway.

Patient participation is a right that has been legislated internationally in recent decades (Helse- og omsorgsdepartementet, 2015b; Norwegian Ministry of Health and Care Service-

Patients and User Rights Act, 1999; Organization, 2013; Thompson, 2007), with various theories being developed to explain the meaning of the term (Bårdsgjerde, 2022; Castro et al., 2016; Landstad et al., 2020; Thompson et al., 2007). Patient participation occurs through mutual relationships that are characterised by shared willingness and two-way communication built on openness and mutual respect between patients and healthcare professionals (Thompson et al., 2007; Thompson, 2007).

Compassionate care is not legislated; however, it is an international term used to describe particular qualities of care (Brito-Pons & Librada-Flores, 2018; Devik et al., 2020). Compassionate care is considered a core value in nursing and essential in palliative care (Larkin, 2016). Compassion is also highlighted in health policy documents. In England, Compassion in Practice was launched in 2012 by Jane Cummings, who was the Chief Nursing Officer for England, and Viv Bennett, who was Director of Nursing at the Department of Health in 2012 (Serrant, 2016). This strategy was built on the values of the 6Cs (Care, Compassion, Communication, Courage, Competence, Commitment) and delivered improvement programmes through six work streams called 'action areas'. The Compassion in Practice Strategy aimed to provide a framework for rebuilding public confidence and reaffirming pride in the health profession (Serrant, 2016).

Although compassionate care and patient participation have different historical and etymological roots, the concepts have common features. Both approaches have common underpinning thoughts about how healthcare personnel should meet the patient and family caregivers. Awareness, sensitivity, and respect for the patient are basic attitudes. Compassionate care can be described by words that the Victorians included under the category of 'open-heartedness': it is kind, gentle, warm, loving, affectionate, caring, sensitive, helpful, considerate, sympathetic, comforting, reassuring, calming, open, concerned, empathetic, friendly, tolerant, patient, supportive, encouraging, non-judgemental, understanding, giving, soothing, validating, respectful and attentive (Crawford et al., 2014). In comparison, Thompson's presentation of emotional reciprocity is based on patients' opportunity to express emotions and health personnel's response to these (Thompson et al., 2007).

The different concepts used in the thesis have both similarities and differences. As family caregivers, nurses, and physicians were interviewed, patient participation and family involvement were the theoretical approaches that initially seemed most appropriate to highlight important findings in the studies. Interesting findings emerged in the focus groups with the nurses to elucidate compassionate care in different phases of the pathway. The nurses in our study talked about participation, but the most interesting substantial were about care. This was one of the reasons why we saw compassion as the most appropriate concept in the interview study with the nurses. My preunderstanding derived from my career as a cancer nurse. I view compassionate care as essential in caring for patients and family caregivers and know that compassionate care can create a space for participation and involvement.

Thompson uses terms such as shared decision-making, autonomy, and concepts from ethical theory, and the physicians in the study talked a lot about the ethical reasoning associated with patient participation (Thompson et al., 2007; Thompson, 2007). Therefore, the biomedical principles (Beauchamp & Childress, 2019) provide a valuable complementary perspective to include in the analysis of Study III.

4 Aims of the thesis

The overall aim of this thesis was to obtain knowledge about patient participation, family involvement and compassionate care as experienced by family caregivers and health personnel in the different phases of the palliative cancer care pathway.

The specific aims and research questions of the three studies are presented in Table 1.

Table 1. Aims and research questions

	Study I	Study II	Study III
Aims	Explore how family caregivers experience information and involvement in the different phases of palliative care.	Explore how nurses experience compassionate care for patients with cancer and family caregivers in different phases of the palliative pathway.	Gain knowledge of physicians' perspectives on patient participation and family caregivers' involvement in palliative cancer care.
Research questions	How do family caregivers experience information and involvement in the different phases of palliative care?	How do nurses experience compassionate care for patients with cancer and family caregivers in different phases of the palliative pathway?	How do physicians perceive patient participation and family caregivers' involvement in the different phases of the palliative pathway?

5 Study design

We have chosen a qualitative design for this research project, and this includes both methodology and methods (Creswell, 2014). Qualitative research is described as an approach to explore and understand the meaning individuals or groups assign to a social or human problem (Creswell, 2014). The overall aim of the project was to obtain knowledge about patient participation, family involvement, and compassionate care as experienced by family caregivers and health personnel in the different phases of the palliative cancer care pathway. We want to explore and understand how family caregivers, nurses, and physicians experience these phenomena. Given this aim, a qualitative design was an appropriate approach (Creswell, 2014; Denzin & Lincoln, 2018; Flick, 2022; Holloway & Wheeler, 2010).

We have chosen a narrative and a hermeneutic approach in the different studies (Alvesson & Sköldberg, 2018; Chase, 2005; Gadamer, 1989; Gilje, 2019; Holloway & Freshwater, 2007; Holstein & Gubrium, 2012; Josselson, 2011; Malpas & Gander, 2015; Wertz, 2011). As we wanted to illuminate the research question from the perspective of family caregivers and healthcare personnel, it was appropriate to choose interviews as the method for acquiring information on participation, involvement, and compassionate care. The narrative and hermeneutic approaches gives the informants a clear voice.

5.1 Methodology

'Methodology' refers to the framework within which the research project is conducted (Braun & Clarke, 2013), for example, narrative and hermeneutics. 'Methods' refers to techniques for collecting and analysing data, such as individual interviews and focus groups for gathering data and thematic analyses as a way to analyse the data collected (Creswell & Creswell, 2018).

Ontology, epistemology, values, and methods are four different assumptions I, as the researcher, have held in the execution of the research project (Creswell, 2014). The methodology is the bridge that brings my philosophical standpoint (on ontology and epistemology) and method (perspective and tools) together (Hesse-Biber & Leavy, 2010). Our approach to the qualitative research holistic. A holistic approach is attentive to the important connections between the philosophical framework and methods employed. A holistic approach explicitly integrates ontology, epistemology, methodology, and methods. In other words, a holistic approach requires us not to disfavour our underlying thoughts but rather to examine how our ontological and epistemological perspectives impact methodology. Therefore, I view this holistic research approach as a process rather than an event (Hesse-Biber & Leavy, 2010). In this regard, adopting a holistic approach means that in this research project we view all research choices, from topic selection to final representation, as interrelated.

Ontology is the study of the world and what is in it (Bukve, 2016); it is about how we perceive the part of the world we want to study. Ontology precedes epistemology (Justesen & Mik-Meyer, 2010). Braun and Clarke (2013) describe three different approaches to knowledge: realism, relativism, and critical realism. In realism, one assumes that there is a truth to achieve and that it is reachable with the proper techniques often used in quantitative research. Relativism argues that there are constructed realities and that one can never go beyond these constructions often used in constructivism research (Braun & Clarke, 2013). I see our project within critical realism where the position falls somewhere in between, seeing a real and knowable world behind the subjective and socially located knowledge; this position is quite common in qualitative research (Braun & Clarke, 2013).

Epistemology is the study of knowledge and knowledge formation, including how we gain knowledge about the world (Bukve, 2016). Epistemology considers how knowledge is found (Justesen & Mik-Meyer, 2010), the methods by which we obtain knowledge, and our capabilities for obtaining it (Madsbu, 2011). In our project, the methods used were individual interviews, focus groups, and thematic analyses.

5.1.1 Narrative approach

In the first study we used a narrative approach that included individual interviews as well as a narrative approach to the analysis of the data (Chase, 2005) with coding of data related to the beginning, the middle, and the end to highlight the different phases in the palliative pathway (Josselson, 2011).

There are many understandings of narrative research, and the definition of narrative has changed over time (Chase, 2005). American sociologist and researcher Susan E. Chase (2005) describes a development from using narrative exclusively to illuminate the past and present to the inclusion of the future in narrative presentations. Narrative approach was considered an appropriate way to study participation in a patient pathway as, in our study, the palliative pathways have a time perspective and chronology of events (Chase, 2005; Denzin & Lincoln, 2018; Holloway & Freshwater, 2007; Josselson, 2011; Landstad & Kvangarsnes, 2020). The narrative can be based on experiences related by one informant or by several (Brinkmann & Kvale, 2015). Our study is based on information from several informants.

Narratives are essential for examining human experiences, actions, and understandings (Chase, 2005; Holloway & Freshwater, 2007; Holstein & Gubrium, 2012; Wertz, 2011). Josselson (2011) states that there are many different ways to conduct narrative research, but one typically focuses on narrated text representing an entire life story or aspects of it. Further, she says that people live and understand their lives in story form. Stories have a beginning, a middle, and an endpoint, connecting events in the manner of plots. Life stories depend on the context, selection of what to tell, experiences, and understanding.

The narrative approach was relevant in our study of family caregivers to illuminate participation and involvement from their perspectives. In the interview guide, we used open-ended questions to get them to talk about participation and involvement. We found the different phases of the palliative pathway suitable for the chronological timeline of narrative storytelling: the early phase (the beginning), the middle phase (the middle), and the terminal phase (the endpoint). In narrative analysis, one searches for a plot which is a pattern of developments in the stories (Holloway & Freshwater, 2007; Holstein & Gubrium, 2012; Patton, 2015). In our study, the plot described participation and involvement in the different phases of the pathway. The interviews were presented as a single narrative representing a composite interpretation of all the family caregivers' stories.

The narratives in the participants' stories were shaped by the interaction between the family caregiver and me as an interviewer (Chase, 2005), as well as by how the other researchers and I interpreted the data. As a researcher, I was a qualitative research co-creator, particularly in narrative storytelling (Holloway & Freshwater, 2007; Holstein & Gubrium, 2012).

5.1.2 Hermeneutic approach

Hermeneutics focuses on the interpretation of meaning and asks questions of the text (Gadamer, 1989). *Hermenuein* means 'to express' in the sense of conveying and speaking. The meaning of the word is three-fold: to express, to interpret, and to translate (Gulddal &

Møller 1999). The text in our studies is qualitative interviews. The purpose of hermeneutic interpretation is to achieve a trustworthy and in-depth understanding of the text. Ricoeur writes that man is a historical being with prior knowledge of tradition and historical life, and Gadamer argues that this understanding carries the prejudice that texts can provide meaning from context (Gadamer, 1989).

The origins of hermeneutics can be traced back through history. The Croatian-Italian Matthias Flacius (or Flacius Illyrius) lived in the 16th century and was preoccupied with biblical hermeneutics. He said we must try to find the genre to which the text belongs, the so-called 'rule hermeneutics'; this was mainly within the 17th and 18th centuries (Krogh, 2014).

In 1808, the German Friedrich Ast published the work 'Basic principles in grammar, hermeneutics, and criticism'. Ast was among the first to focus on the phenomenon of 'the hermeneutic circle.' The basic idea of the principle for understanding a text, which was eventually called the circle of understanding or the hermeneutic circle, is old in the hermeneutic tradition (Krogh, 2014). The German Friedrich Schleiermacher was a theologian and a crucial hermeneutic theorist in the first half of the 19th century. He gave the hermeneutic circle a central position in interpretation, both in text and verbal dialogues (Gulldal & Møller, 1999).

The research group acknowledge that our prejudices are the precondition for our understanding (Gadamer, 1989). Gadamer (1989) acknowledges that our prejudice and our preconceptions are a prerequisite for all understanding and experiences, and that all understanding is self-understanding. Heidegger argues that hermeneutics is a self-reflexive, interpretive, ontological inquiry. This idea tends to be dominant in the 20th century within philosophical hermeneutics, which we can see in both Gadamer's and Ricoeur's work (Malpas & Gander, 2015).

We viewed hermeneutics as an appropriate approach for exploring primary care nurses' and physicians' different experiences of patients' and family caregivers' participation. My prejudices have been central, and I have clarified in advance the terms 'patient participation', 'family involvement', and 'compassionate care'. In the hermeneutic approach, I, as a researcher, am aware of being a participant and producer of new knowledge as the data are collected, analysed, and interpreted (Gadamer, 1989). Throughout the entire research project, my understanding has been central (Gilje, 2019) as I have worked closely in the field I am researching. In addition, I have worked personally and through discussions with co-authors to make my preconceptions visible. I have in the entire process focused on emerging patterns of interpretation between my preunderstanding and understanding, seeing the whole text developed by the interpretation of the parts and the parts illuminated by the whole (Alvesson & Sköldberg, 2018). This might also have been a benefit in revealing the 'true story' since I have a profound knowledge of the settings (Alvesson, 2003).

In Studies II and III, we were inspired by Gadamer's philosophy of preunderstanding and the hermeneutic circle. The hermeneutic circle was central to interpret the underlying meaning of participation, involvement, and compassionate care in the different phases of the palliative pathway. In the hermeneutic analysis in Studies II and III, using the hermeneutic circle, the meaning of the parts (the three different phases) depended upon the whole (the pathway), and the whole depended upon the parts (Alvesson & Sköldberg, 2018). By transforming the hermeneutic circle into a spiral, one can delve further and further by alternating between the part and the whole, creating a deeper understanding (Alvesson & Sköldberg, 2018). There is a unique awareness of how pre-understanding can influence data interpretation (Gadamer, 1989), and in our group discussions my co-authors and I have developed new understandings (Brinkmann & Kvale, 2015). There are two directions within hermeneutics: the objective and the aletic. The objective direction is the circle of the part and the whole; the aletic direction is the circle of understanding and pre-understanding. These circles are complementary to each other rather than opposed (Alvesson & Sköldberg, 2018). In the process of analysing the pattern of interpretation, textual analysis, dialogue, and sub-interpretation lead to the basic hermeneutic circle; we have strived to achieve a balance between the whole and the parts and between our pre-understanding and understanding (Alvesson & Sköldberg, 2018).

The knowledge acquired in one situation might not be transferred to another situation (Brinkmann & Kvale, 2015). Human life and understanding, in general, are contextual. We have tried to bring out understanding and interrelationships to expand and create meaning in the text (Brinkmann & Kvale, 2015). This is in line with Gadamer's understanding of the dialogical meeting with the text, in which he claims to see beyond what is immediately understood. The interpretive work sets in when an event or text is not immediately available to us because our horizon of understanding is too different from the one being interpreted (Gadamer, 1989).

5.2 Methods

Qualitative methods can be used to describe, analyse, and interpret different qualities of the phenomenon being studied (Malterud, 2017) and is ideal for exploring experiences within palliative care (Lim et al., 2017).

Data were collected using individual interviews and focus groups (Brinkmann & Kvale, 2015; Holloway & Freshwater, 2007; Krueger & Casey, 2015; Patton, 2015; Polit & Beck, 2012). The three studies examined the various phenomena from the perspective of the informants. We considered interviewing patients but found this challenging within the allocated framework. Nevertheless, we considered family caregivers and healthcare personnel to be a good sources of information to the different phases of the palliative pathway.

When we designed the study, we first divided the pathway into three phases following Grov`s model (2014), but when we started interviewing family caregivers, we saw a need to divide the terminal phase into two subparts (terminal phase and bereavement phase). In Studies II and III, we divided the pathway into three phases as originally planned. The design of the studies is summarised in Table 2.

Table 2. The various qualitative designs

STUDY	APPROACH	PARTICIPANTS	DATA COLLECTION	ANALYSIS	THEORETICAL PERSPECTIVE
Study I In-depth interviews with family caregivers	Narrative approach	11 family caregivers	Individual interviews	Narrative analysis	Thompson's theoretical perspective of involvement
Study II Focus group with primary care nurses	Hermeneutic approach	21 primary care nurses	Focus groups	Hermeneutic analysis	Compassionate care
Study III In-depth interviews with physicians	Hermeneutic approach	13 physicians	Individual interviews (video interviews)	Thematic analysis	The four ethical principles and Thompson's theoretical perspective of involvement

In Study I we used qualitative interviews with a narrative approach, and the analysis was inspired by Thomson's theoretical framework in an inductive process in which we worked back and forth between the themes and the transcripts until we had established a comprehensive set of themes. Then we deductively looked back at the data from the themes to find more evidence to support each theme. Thus, we worked inductively, but we also had deductive thinking moving the analyses forward (Creswell, 2014). Study II used focus groups guided by the theoretical framework of compassionate care. Study III used in-depth interviews and a thematic analysis guided by Thompson and the four principles of biomedical ethics. Moreover, all three studies were guided by the research aims and research questions. The voices of the family caregivers served as the starting point as this data was collected and analysed prior to the interviews with health personnel. We wanted to examine the experiences of healthcare personnel in the field, and as physicians and nurses may have different experiences and perceptions of the pathway, it was appropriate to include both groups

This thesis encompasses three qualitative studies. To collect data, we used individual interviews (Study I and Study III) and focus groups (Study II).

5.2.1 Interviews

We chose *individual interviews* in study I and III. Individual interviews are commonly used in qualitative research (Brinkmann & Kvale, 2015; Patton, 2015). Using interviews in qualitative research generates insight into specific subjects and gives the researcher access to lived experiences (Brinkmann & Kvale, 2015).

In our study of family caregivers, we used individual interviews with a narrative approach. In the narrative approach, it is essential to ask open questions, balancing openness and the interaction with the researcher (Holloway & Freshwater, 2007). The interview guide consisting of a few open questions (Appendix 1). We invited family caregivers to participate because they had experience related to the topic of study, and we wanted them to share detailed accounts of experiences through individual interviews (Polit & Beck, 2012). We saw individual interviews as suitable because the family caregivers were sharing information about situations of vulnerability (Brinkmann & Kvale, 2015; Patton, 2015).

When we interviewed the physicians, individual interviews was suitable for getting detailed access to experiences (Polit & Beck, 2012) of participation and involvement. We wanted to collect data both across geography and municipalities, and across the specialist health service and primary health service to increase variations of our material. We wanted reference frames from various medical groups in different geographical locations, and physicians with experience from the different phases of the palliative pathway.

In the *focus groups,* we focused on creating a calm atmosphere, letting the nurses speak freely but involving all of them (Brinkmann & Kvale, 2015). We were looking at different perspectives regarding topics in the interview guide (Brinkmann & Kvale, 2015), and following the interaction between the participants (Malterud, 2012). We saw focus groups as suitable for exploring how people in a homogeneous group understand a pre-determined topic: nurses experiences of compassionate care in the palliative cancer pathway (Krueger & Casey, 2015). The dynamics between the participants can created lines of association that open new stories (Malterud, 2012). Interaction in a group may prompt stories about experiences different from those that would have emerged in an individual interview (Malterud, 2012). We saw focus groups as a suitable research method for exploring experiences, attitudes, and views within palliative care following the different phases in the pathway. We considered it essential to find a balance between homogeneity and variation in the groups to elicit varied experiences concerning the different phases of the pathway and the topic under study. In our study, participating nurses in each focus group came from both nursing homes and primary care. Although there was variation in the group, which contained specialised and general nurses from municipalities of different sizes, there was homogeneity as well, as all worked in primary health care and possessed experience with palliative care. We considered focus groups an appropriate approach to obtain varied information and deeper insight into care, participation, and involvement in the different phases of the pathway.

The studies used interview guides with semi-structured or narrative questions. We adapted the interview guide to the research questions in the different studies and to the informants. In addition, we made minor changes while the data collection was in progress based on the interview responses we had already received. We asked follow-up questions in the focus groups. Likewise, there was a need for more follow-up questions in the interviews with the physicians, such as: ‘Can you elaborate on this further?’ or ‘Did I understand correctly, you mean…?’ I tried to make it possible for everyone to express their views in the focus groups.

5.2.2 Thematic analysis

Thematic analysis can serve as a foundational method for qualitative analysis and can provide core skills for other forms of qualitative analysis (Braun & Clarke, 2006). Braun and Clarke argue that thematic analysis should be considered a method in its own right. Thematic analysis is widely used for identifying, analysing, and reporting patterns or themes within the data (Braun & Clarke, 2006). There are four different varieties of thematic analysis: inductive TA, theoretical TA, experiential TA, and constructionist TA (Braun & Clarke, 2013). In Study III, we used inductive TA, analysing from the bottom up using the theory as a lens in the analysis.

Braun and Clarke (Braun & Clarke, 2006, 2013) have developed a step-by-step guide for performing thematic analysis. In Study III, these steps, combined with a hermeneutic approach, guided the analysis. This step-by-step process is not a linear one; we moved back and forth as needed, and the teams developed over time (Braun & Clarke, 2006). Brown and Clarke establish six phases of thematic analysis as described in Table 3.

Table 3. Phases of thematic analysis (adapted from (Braun & Clarke, 2006)

Phase	Description of the process
1. Familiarising yourself with the data	Transcribing data (if necessary, reading and re-reading the data, noting initial ideas).
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set and collating relevant data.
3. Searching for themes	Collating codes into potential themes and gathering all relevant data.
4. Reviewing themes	Checking whether the themes work in relation to the coded extracts (Level 1) and the entire dataset (Level 2) and generating a thematic ‘map’ of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme and the overall story and generate clear definitions and names for each theme.
6. Composing the report	The final opportunity for analysis. Selecting vivid, compelling extract examples, analysing selected extracts, relating the analysis to the research question and literature, and producing a scholarly report of the analysis.

5.3 Study I

The empirical data in Study I consist of narrative interviews (Brinkmann & Kvale, 2015; Chase, 2005). Eleven family caregivers were interviewed about their experiences with participation and involvement in the different phases of the palliative pathway. A narrative analysis was performed.

5.3.1 Participants

The purpose of this study was to explore family caregivers' experiences with the different phases of palliative cancer care; participants were chosen because they had experienced being close to a patient needing palliative care. We employed purposive sampling of 11 family caregivers (Brinkmann & Kvale, 2015; Creswell, 2014) who met the following inclusion criteria: they had followed the patient closely through palliative care; they had cared for a patient who had received services in both primary and specialist healthcare; they spoke fluent Norwegian; they were older than 18 years; they had lost their relatives to cancer 3–12 months before the interview.

A cancer nurse in each municipality recruited the participants, with small, large, and urban municipalities being selected to include a range of backgrounds. We asked six different municipalities: two responded that they had no family caregivers, and four recruited participants. The participants first received an oral request, and if they said yes, they received written information before confirming participation. I then contacted them by phone to arrange a meeting.

The sample consisted of two men and nine women aged 35–77 years. Two participants were adult children, and nine were spouses. The participants themselves chose where to be interviewed. Nine were interviewed in their homes and two in the municipal centre.

5.3.2 Data collection

The interview guide (Appendix 1) was composed of narrative questions based on previous literature and the study's aim (Brinkmann & Kvale, 2015). Each interview began with the opening question, 'Can you freely tell a little about how you have experienced the palliative process if one divides it into three parts: the early phase, middle phase, and the last phase?' along with an explanation regarding the three phases. The participants told their stories from beginning to end within the different phases of the pathway, recounting their experience of participation and involvement.

The face-to-face interviews were conducted between November 2016 and May 2017. In each interview, only the participant and I, were represented. The interview guide (Appendix 1) was used to provide a framework. There was little need to refer to the interview guide, and follow-up questions were asked only when necessary to extend the conversation (Brinkmann & Kvale, 2015). For me, it was essential to follow the participants' narratives (Holloway & Freshwater, 2007), encouraging the family caregivers to lead the interviews in telling their stories. It was important for me, as an interviewer, to adopt the role of narrator and listener, respectively (Brinkmann & Kvale, 2015; Chase, 2005; Holloway & Freshwater, 2007; Patton, 2015). I tried to follow the participants' stories, not concentrating on writing detailed field notes but rather jotting down keywords to use afterward. At the end of each interview, I used keywords to ask follow-up questions and wrote field notes to use in transcription and reflections with my research group. The open-ended questions posed to the family caregivers focused on the pre-defined phases of palliative care. The goal was to create an open approach to sharing their stories with little interruption from me as a moderator (Brinkmann & Kvale, 2015).

All 11 informants showed a desire to tell their stories. The family caregivers were emotionally affected by telling their stories. Having an advance agreement with cancer nurses for an interview follow-up, I asked each participant after the interview whether they wanted to speak with a cancer nurse after concluding. One responded yes because she wanted a conversation with those who had been present when her husband died.

My research group and I agreed upon saturation when the interviews provided thorough answers with rich and diverse data tending to become repetitive (Creswell, 2014; Saunders et al., 2018).

5.3.3 Data analysis

An inductive approach was adopted in analysing the interviews, focusing on the narrative plot (Holloway & Freshwater, 2007). In addition to a plot, a narrative also includes expressions of emotions, interpretations, and thoughts (Holloway & Freshwater, 2007), and I as the researcher searches for what they want to tell, considers what it is about, and their emotions about the material. This analyse process became a part of the transcript. Each interview was audio-recorded and lasted between 50 minutes and three hours. The interviews were transcribed verbatim by me (Creswell, 2014; Polit & Beck, 2012). First, I obtained a holistic impression of the interviews (Brinkmann & Kvale, 2015) by listening to the recordings and reading the transcripts several times. Guided by Thompson's theory of involvement (Thompson et al., 2007; Thompson, 2007), I then identified meaningful units related to the different phases of the palliative pathway. The initial coding of themes based on the phases of the palliative care pathway and the study's theoretical framework (Thompson, 2007) was central to developing themes that could reveal how the participants experienced involvement in the different phases of the palliative pathway.

Next, the research group discussed the transcripts and meaningful units. Focusing on content, form, and context in the storyline of the interviewees, we identified a theme for each phase and organised the story into a chronological structure (Josselson, 2011; Patton, 2015). Dividing the palliative pathway into chronological phases seemed like a logical structure with which to organise their stories from the beginning to the middle and the end. The data were coded based on these phases and the participants' experiences of involvement throughout the first phase, from the beginning of the palliative pathway, through the middle phase, and towards the end, the terminal and then the bereavement phase.

All interviews formed a part of the analysis, but some made a more vital contribution to the story assembled at the end (Holstein & Gubrium, 2012). In addition, we focused on the similarities and differences between the narratives (Holloway & Freshwater, 2007). Finally, we built the themes by organising the data into increasingly more abstract units, looking for patterns, diversity, and contradictions to break the patterns—all the time exploring the whole of each story as illuminated by the parts (Josselson, 2011). The inductive process involved working back and forth between the data and the themes until the research group had a comprehensive understanding of the interviews (Creswell, 2014). Selected quotations underpinned the themes.

As a research group, we worked together in the analytics process, and various interpretations helped develop an inter-subjective understanding of the narratives (Wertz, 2011). The research group saw the different phases of the palliative pathway as giving a logical structure to the compiled narrative. Moreover, the perspectives of both the participants and the research group were essential in identifying themes through patterns developed in the analytic process (Denzin & Lincoln, 2018).

5.4 Study II

The empirical data in study II consisted of focus groups with a hermeneutic approach (Gadamer, 1989; Krueger & Casey, 2015). Twenty-one nurses from primary care were interviewed about their experiences with care in the different phases of the palliative pathway. A hermeneutic analysis was performed.

5.4.1 Participants

The purpose of this study was to explore the experiences of primary care nurses of compassionate care in the different phases of palliative cancer care. Participants were chosen because they had experience working closely with patients and family caregivers in need of palliative care. We employed purposive sampling (Brinkmann & Kvale, 2015; Creswell, 2014; Krueger & Casey, 2015), selecting 21 nurses who met our inclusion criteria, which were that they had worked bedside with palliative care in a primary care context for more than three years and spoke fluent Norwegian. Administrative nurses were excluded.

Recruitment began with permission from the municipal manager, who named a contact person. Ongoing dialogue in the recruitment process took place between the contact person and relevant informants. Seeking diversity, we included nurses from home care and institutional care who worked 'bedside' because they would have experience with palliative care. Furthermore, we included nurses from urban and rural areas to increase the range of our data. The participants worked in various municipalities in Mid-Norway with populations ranging from 2,000 to 50,000 inhabitants.

The participants received an oral request, and if they said yes, they received written information before confirming participation. The municipality contact person assigned the participants a meeting place and time; the focus groups took place in rooms shielded from noise in municipal institutions. Each of the four focus groups had between three and seven participants. Two nurses did not attend one focus group, leaving the group with three participants. The sample consisted of 21 female nurses, eight of whom specialised in oncology or palliative care. The nurses' ages ranged from 28 to 60 years; they all had more than three years of experience with palliative care and spoke fluent Norwegian.

5.4.2 Data collection

We chose a focus group format to obtain data for this study. We reasoned that exploring nurses' experiences through discussions with other participants with whom they had something in common would promote self-disclosure (Brinkmann & Kvale, 2015; Krueger &

Casey, 2015; Malpas & Gander, 2015). The data were collected in 2019. The interviews in the public health centres were not conducted in the nurses' places of employment.

In our study, the range of backgrounds among nurses from both institutions and home-care settings prompted different stories as they built upon one another's narrations. Differences in educational background (we included general nurses, oncologic nurses, and palliative nurses) contributed to bringing different perspectives into the group discussions. The interview guide (Appendix 1) for Study II was composed based on the results of Study I, and we added more questions concerning care and family caregivers (Krueger & Casey, 2015). I conducted the focus group interviews, and an experienced researcher (MK) participated as an assistant, took field notes, asked follow-up questions when needed, observed group dynamics, and summarised the nurses' responses at the end of the interviews. Participants were invited to comment or supplement their comments. As the moderator, I let the discussion flow naturally between participants, and they were allowed to speak openly and participate in the focused discussion (Krueger & Casey, 2015). The participants were engaged and open, especially in discussions between nurses working in nursing homes and home-care nurses.

The focus groups lasted between 60 and 90 minutes. They were audio-recorded and transcribed verbatim by me (Krueger & Casey, 2015; Polit & Beck, 2012). The informants were provided anonymity, being assigned the letters A, B, C, D, E, F, and G starting from the left. In addition, the focus groups were numbered 1, 2, 3, and 4. The assistant and I discussed the context and participation following each interview; this became a part of the transcript. All the authors discussed data saturation; after four focus groups, we considered the data to be saturated; the data tended to become repetitive and redundant. Data collection and analysis went hand in hand (Patton, 2015).

5.4.3 Analysis

Analysing focus groups requires a clear purpose and a systematic approach (Krueger & Casey, 2015). The transcripts and field notes based on interactions and group dynamics were used to identify nurses' experiences, meanings, and discussions. As the first author, I coded the transcript into an early palliative phase, a middle palliative phase, and a terminal phase. All the authors read the interviews to gain a holistic impression of the data (Brinkmann & Kvale, 2015). We actively used the hermeneutic circle in the analyses. The study's theoretical framework shaped our prejudices and pre-understandings, which was valuable for identifying perceptions of compassionate care in the data. In analysing the data, we moved between the different phases and the whole pathway and across the transcript to elucidate similarities, patterns, and variations in the data.

Consequently, we gained a new and deeper understanding of compassionate care in the different pathway phases—both for patients and their family caregivers. The theoretical perspective of compassionate care brought a new understanding of how this is experienced in practice—for example, through the theme ‘creating a place for dying’. In the process of interpretation, it was essential to read the transcript with empathy and consider how this was related to participation, involvement, and compassionate care. This way of reading enriched our previous interpretations, and our notes on the interaction and context of the interviews were highlighted. We confirmed the themes by comparing them with the transcripts (Krueger & Casey, 2015). Movement from the whole to the different phases and back to the whole pathway was essential (Gadamer, 1989). Furthermore, the perceptions of the nurses' care experiences were central (Alvesson, 2003). We discussed interpretations and our findings through the process to obtain a deeper and shared understanding. Our different clinical practices within nursing, medicine, and social sciences and our different academic backgrounds were valuable in contributing to a broader understanding. In addition, these discussions with the other researchers were valuable in moderating my preunderstanding based on working in the field for several years.

5.5 Study III

The empirical data in Study III consisted of individual interviews, and a thematic analysis (Braun & Clarke, 2006, 2013) using a hermeneutic approach (Brinkmann & Kvale, 2015; Gadamer, 1989; Gilje, 2019; Malpas & Gander, 2015) was performed.

5.5.1 Participants

The purpose of this study was to explore physicians’ perceptions of patient participation and family involvement within the different phases of palliative cancer care, and the participants were chosen because they had experience working closely with a patient in need of palliative care. Thirteen Norwegian physicians treating palliative care patients were recruited through purposive sampling (Brinkmann & Kvale, 2015; Creswell, 2014), and the inclusion criteria were physicians being responsible for the medical treatment of patients receiving palliative care. In particular we wanted physicians who were in contact with patients and family caregivers within primary care services.

Both palliative care physicians and GPs treating palliative cancer-care patients were included. We chose to include both GP and physicians working in hospitals with palliative care to get a broader perspective on patient participation and involvement. The inclusion criteria sought physicians with experience working with palliative care and with patients and family caregivers using primary care services. Their level of experience varied from 10 to more than 30 years. In Norway, the organisation of care and the responsibility for it can differ between local hospitals. To get a broader view of practice, we chose to include physicians with different perspectives. We envisioned that the physicians would have different responsibilities in the different phases of the patient trajectory. This difference, along with their different organisational affiliations, would help us represent a wide range of experiences through the different phases of the pathway.

A contact person in the health care system recruited the physicians. The participants received a written request, and if they said yes, they received written information before confirming participation. I then contacted them by mail to arrange a meeting. Fifteen physicians were invited to participate, and 13 accepted. The physicians came from different parts of Norway, including rural communities and larger cities, and were recruited from both local and regional hospitals. Unfortunately, due to the COVID-19 pandemic, all interviews had to be conducted as video interviews via Skype or Teams.

5.5.2 Data collection

The purpose of these interviews was to explore physicians' experiences with the different phases of the palliative pathway. I conducted in-depth video interviews between April and May 2020. The interview guide for Study III was composed based on results from Studies I and II. The questions related to physicians’ experiences with participation and involvement in the different phases of the palliative pathway: the early phase, the middle phase, and the terminal phase. The interviews lasted between 35 and 60 minutes. Only the participant and I were present during each interview. The demographic data from some participants were sent via mail, while some provided demographic data during the interview. The in-depth interviews were conducted in an open dialogue and were led using the interview guide (Appendix 2) as a checklist. The individual interviews with physicians presented new situations for the participants and me as a moderator since the interviews were conducted via the internet. Not all the participants were familiar with Skype or Teams, and some had to practice beforehand. We focused on early participation, dialogue, and family involvement in the interviews. The goal was to create an open approach for the physicians to speak freely about their experiences in palliative care. In some of the interviews, I had to ask several follow-up questions, while in others, I asked almost none. When the interviews seemed to provide no new information, the authors discussed saturation (Brinkmann & Kvale, 2015).

5.5.3 Analyses

The interviews were audio-recorded and transcribed verbatim by the first author. Summary notes were written after each interview and used in discussions with all co-authors. In addition, all authors read the interviews to gain a holistic impression of the data (Brinkmann & Kvale, 2015).

We were inspired by Braun and Clarke's six steps (Braun & Clarke, 2006, 2013) of thematic analysis. According to Braun and Clarke (2013), thematic analysis is suitable for generating insight into similarities and differences across the data set. It is an appropriate method for obtaining rich and detailed descriptions of informants' experiences. Performing thematic analyses was not a linear process; there was constant back-and-forth movement through the dataset several times in each of the phases. First, all the authors read and re-read the transcribed interviews and noted initial ideas. We discussed the overall understanding of the different phases revealed in the dataset. For example, I, as the first author, coded the interviews related to participation in the early, the middle, and the terminal palliative phases. Second, the authors together constructed a coding tree guided by the four ethical principles: autonomy, non-maleficence, beneficence, and justice (Beauchamp & Childress, 2019). I listened to the audio recordings to check the transcripts for accuracy, looking for meaningful units in the transcript and making notes in the margins. I used markers of different colours to distinguish between the three different phases. Meaningful units were gathered and discussed with the co-author several times (Brinkmann & Kvale, 2015). Third, the authors searched for themes and central quotations and inserted them into the coding tree. In the fourth step, all the authors discussed and re-wrote the themes after exploring differences in the joint discussion. Fifth, to finalise the themes, we studied the dataset and discussed the findings. Finally, I wrote the results section, obtaining feedback from the other authors in the writing process. In addition, Thompson's theoretical framework (Thompson et al., 2007; Thompson, 2007), focusing on participation and involvement, was used as a guide throughout the process of analysis.

We were leaning towards a hermeneutic approach with special awareness of the pre-understanding influencing data interpretation (Gadamer, 1989). We developed a new understanding through group discussions in which all authors were engaged (Brinkmann & Kvale, 2015). Thus, we developed a deeper understanding of physicians' perceptions of patients’ and family caregivers' participation in the different palliative pathway phases (Gadamer, 1989).

5.6 Ethical considerations

Our qualitative research project deals with vulnerable life situations. Therefore, ethical considerations were essential both during the project's planning and in implementing the various studies. Ethical considerations were not primarily connected to the interview situations but rather were seen as a part of the whole research project (Brinkmann & Kvale, 2015). Ethical considerations informed planning, formulation of the research question, interview situations, transcription, analysis, verification, and reporting (Brinkmann & Kvale, 2015).

All participants received written information about the project before agreeing to participate. In addition, the same information was provided before each interview. Each participant signed informed consent and allowed the material to be used in future research (Brinkmann & Kvale, 2015). The family caregivers were given the option to be interviewed in their homes or at a community centre. We, as a research group, ensured the participants' anonymity and confidentiality in written information. We were careful to use an appropriate language style to preserve dignity in publication, which was especially important when writing quotations.

Precautions to protect the privacy and confidentiality of the information collected about participants are important (World Medical Association, 2013). The Norwegian Research Ethics Committee in Mid-Norway (2016/978/REK NORD and REK78067) waived the need for approval for each study. The Data Protection Officer in Møre og Romsdal Hospital Trust (2016/960-25) approved Study I and Study II. The Norwegian Centre of Research Data (NSD131948) and the Data Protection Officer in Møre og Romsdal Hospital Trust (HMR2020/397-2) approved Study III. In line with the Norwegian Centre of Research Data and the Data Protection Officer in Møre og Romsdal Hospital Trust, the material will be stored for five years before being deleted or anonymised. De-identified data (audio recordings, field notes, and transcripts) are kept on a password-secured server, as indicated in the recruitment paper signed by the participants. The written consents, as well as my field notes, are stored in a locked cabinet in the Møre og Romsdal Hospital Trust. We have replaced participants' names, ages, gender, and place of employment with numbers to ensure confidentiality.

Due to my close relationship with the research field, it was crucial in the presentation of results to collaborate closely my supervisors. We have focused to present the findings as representative, accurate, and transparent as possible (Brinkmann & Kvale, 2015).

5.6.1 Ethical reflections

In the study of family caregivers, a cancer nurse working in each municipality recruited the participants. The recruitment occurred three to twelve months after the patient had died. Conducting interviews earlier than three months could be perceived as too early for family caregivers, as they could be in an active grieving process. After twelve months, it could be too long to remember the intimate story. We thought we could get rich material if the interviews were conducted between three and twelve months after the death. Two municipalities declined because they did not have any participants suitable for the research at that time; both were small municipalities. The cancer nurses reported that some of the participants wanted to participate in order to contribute to research and some because they wanted to share their stories. The participants reacted differently to the timeline. One participant, who had been bereaved four months earlier, remarked that she had forgotten already, since it had been a while. Another participant, who had been bereaved for six months, described it feeling very close to her, 'like it was yesterday'. For me, this stimulated ethical reflection on the need to be sensitive in their mourning process. Furthermore, being aware that some participants knew that I was a cancer nurse led to ethical reflection on my role as a researcher when interviewing.

Vulnerable groups should not be harmed in research (World Medical Association, 2013). We considered the family caregivers a vulnerable group, as the participants were in a vulnerable situation. Many of the participants were emotional during their interviews. It seemed as though telling their stories during the interviews was therapeutic for some participants

(Josselson, 2011). As a researcher, I was bound to refrain from engaging in therapeutic conversation with a person I had never before met (Brinkmann & Kvale, 2015). Personal closeness in a research relationship places substantial demands on the researcher's sensitivity and may affect the interview context. Still, it was essential for me to have basic knowledge of the field I investigated (Brinkmann & Kvale, 2015). I had established the recruiting cancer nurse to serve as a contact person for the participants if needed. One participant requested to speak with the nurses working in the institution where her husband had died. The recruiting cancer nurse arranged the meeting.

Working as a cancer nurse in the municipality, I was aware of the situation in which the research would place me. The interview situation felt similar to practising as a nurse and sitting in the living room talking. I considered the imbalance in power, and to me, it seemed pragmatic to focus on the narrative approach (Brinkmann & Kvale, 2015; Josselson, 2011) and let the participants tell their stories with only minor interruptions from me. One of the participants asked my opinion several times. I responded that it was necessary for me to hear the story without interrupting.

I, as the moderator, informed the focus groups with community nurses of the confidentiality of what was shared in the focus group.

The study of physicians was supposed to begin shortly after the COVID-19 pandemic hit Norway. In the beginning, it was not possible to recruit participants; however, by May and June 2020, participants expressed interest. The interviews were conducted via Skype or Teams and recorded there. Two participants agreed to be interviewed but did not respond to follow-up messages. Out of respect for the individual right to withdraw, I did not attempt to reach them after the first failed attempts. When conducting video interviews, I had no control over whether the interviewee was in a situation where somebody could overhear the conversation. I considered that the physicians were not a vulnerable group and had reasonable control over the question of whom they might want to share the information with.

6 Findings

The aim of the thesis was to obtain knowledge about patient participation, family involvement, and compassionate care as experienced by family caregivers and health personnel in the different phases of the palliative cancer care pathway. In this chapter, I first present the main finding of each of the three studies. Then I present a synthesis of the findings. Table 4 summarises the main themes of the three studies and Table 5 the synthesis of the findings.

6.1 Study findings

Table 4. Summary of main themes in the three studies

Interviews	Theme 1	Theme 2	Theme 3	Theme 4
Family caregivers	Limited involvement in the early phase	Emphasis on patient-centred care in the middle phase	Lack of preparation for the dying phase	Lack of systematic follow-up after death
Primary care nurses	Information and dialogue	Creating a space for dying	Family caregivers' acceptance of death	
Physicians	Beneficence for the patients and the family caregivers in the early phase	Autonomy and shared decision-making in the middle phase	Family involvement in the terminal phase	

6.1.1 Study I

Tarberg AS, Kvangarsnes M, Hole T, Thronæs M, Madssen TS, Landstad BJ. 2019. “Silent voices: Family caregivers’ narratives of involvement in palliative care” *Nursing Open*, DOI: 10.1002/nop2.344 (Tarberg et al., 2019).

This study aimed to explore family caregivers' experiences of involvement in the different phases of the palliative pathway. The family caregivers' narratives comprised four themes in relation to the different phases: 1) limited involvement in the early phase; 2) emphasis on patient-centred care in the middle phase; 3) lack of preparation for the dying phase; and 4) lack of systematic follow-up after the death of the patient.

Limited involvement in the early phase

The family caregivers experienced little involvement early in the process. They felt well informed about the diagnosis but were sparsely involved in discussions about the challenges of care. In most situations, the family caregivers were present at the hospital when the physician informed that the patient had entered the palliative phase. However, several family caregivers expressed a desire to speak with health personnel about the expected disease trajectory and how this could affect their role as caregivers. In addition, family caregivers expressed that they wanted more information about what to expect in the different phases of the illness. Notably, the caregivers' and patients' desires for information were not always congruent. The inability to converse with the health personnel without the patient present could hinder family caregivers' preparation for the different phases of the palliative pathway.

Although patients wished to die at home, several family caregivers expressed ambivalence about this aim. The family caregivers did not feel included in that decision, and some felt it was difficult to fulfil the patients' wishes. The family caregivers expressed that they were given too few opportunities to define their own needs and challenges. The healthcare professionals did not recognise the burden of providing care in the final stages of life, and the family caregivers felt they were left to handle the task on their own. In some cases, the family caregivers expressed to the healthcare providers early in the process that they did not want the patient to die at home. Their reason was in many cases that they did not feel capable of enduring the burden. In cases like this, the family caregivers were listened to, and these patients spent their terminal phase in a primary care institution.

Emphasis on patient-centred care in the middle phase

In the middle phase of the pathway, according to the family caregivers, the focus was mainly on the patient-centred approach. The family caregivers noted that the healthcare personnel took the patients' wishes seriously. However, they expressed that their own needs as family caregivers were often neglected. Some patients' unwillingness to accept help could prevent the family caregivers from enlisting the necessary healthcare service aid, leaving them with too much responsibility. Their role as caregivers overshadowed their role as family members and prevented them from feeling close to the patient. Several said that they did not use the services offered enough or used them too late because they could not predict which services they would need. While patients were treated in a primary healthcare setting, several family caregivers were uncertain about who was responsible for their medical treatment. It felt difficult to understand who was in charge and whom they should contact when in need. In addition, the family caregivers wanted the GP to play a central role in the palliative care pathway. Furthermore, some family caregivers mentioned conflicts of interest with the patients concerning various goals in the palliative pathway.

Lack of preparation for the dying phase

None of the family caregivers talked about involvement in making plans for the terminal phase. The family caregivers experienced this phase as complex, as they did not know what lay ahead. One informant said that she would not have taken on the burden if she had known how challenging it would be. The need for more information about the process of dying was emphasised. Establishing a dialogue with healthcare providers and being listened to were considered essential steps to improve the involvement of the family caregivers in the terminal phase. However, some experienced situations in which patients were unwilling to provide information about their conditions to their family caregivers, thus preventing cooperation between health personnel and family caregivers. When patients were at home, family caregivers often felt alone with the responsibility, and they expressed the need for more information and guidance.

Lack of systematic follow-up after death of the patient

There seemed to be a lack of systematic follow-up after death. Following the patient's death, some family caregivers met with the local community oncology nurse, others met with personnel from the hospital, and some received support from the GP or the local priest. However, most of the informants expressed that there had been no offer of follow-up help. The family caregivers noted that it was vital to talk with the health personnel present on the patient's last day. They had many questions about the process of dying, and obtaining answers to these questions was considered necessary in grieving and moving on with their lives. Some family caregivers mentioned that a discussion after the patient's death might have been valuable to help manage the sorrow and loss; but on the other hand, some had declined such an offer.

6.1.2 Study II

Tarberg AS, Landstad BJ, Hole T, Thronæs M, Kvangarsnes M. 2020. "Nurses' experiences of compassionate care in the palliative pathway" *Journal of clinical nursing*. https://doi.org/10.1111/jocn.15528 (Tarberg et al., 2020).

This study aimed to explore nurses' experiences of compassionate care for cancer patients and their family caregivers enduring the different phases of the palliative pathway. Their experiences comprised three themes following the different phases: 1) information and dialogue, 2) creating a space for dying, and 3) family caregivers' acceptance of death.

Information and dialogue

The primary care nurses emphasised that sharing information and dialogue with patients and family caregivers were important early in the pathway. However, the nurses reported having little opportunity to be involved with advanced care planning, as they often had little contact with patients and family caregivers in the early phase. They considered it vital to plan palliative care with the patients and family caregivers before the patients reached their last stage of life. In the nurses' experiences, a palliative plan should express patients' wishes and needs to maintain patient-centred care. They noted that advanced care planning led to helpful information being presented to patients and family caregivers, creating a sense of security and preparation for what was to come. Health personnel in the hospital play a crucial role in facilitating this early contact between family caregivers and primary care nurses. The nurses also remarked that the patients and family caregivers did not possess sufficient knowledge or experience to understand the importance of early involvement as expressed by the health personnel. Nurses discussed the value of including family caregivers as part of the team because effective collaboration between family caregivers, primary care providers, and healthcare specialists makes it possible to fulfil patients' wishes to die at home. Collaboration was viewed as a vital element of compassionate care.

Creating a space for dying

In the middle phase, the nurses focused on preparing for the patient's last days. The middle phase can include a quiet period in which patients and family caregivers require security, predictability, and clarification. The nurses spoke compassionately about how they facilitated this process by building trust, collaboration, good relationships, empathy, attention, silence, caution, slowness, symptom relief, and the absence of noise and conflicts.

Balancing conflicts of interest among the patients and the family caregivers was a complex task. The nurses highlighted the importance of building trust and strong interpersonal relationships. Conflicts within the family could prevent necessary planning. In some cases, family caregivers held different views of what was best for the patient. Communication skills were an essential competence in providing compassionate care.

Another topic that arose in the focus groups was the importance of nurses having expertise in symptom relief. However, nurses experienced a lack of collaboration with physicians regarding symptom relief which could result in patients not receiving adequate medication in due time. Additionally, nurses sought better system-level planning to provide end-of-life symptom-relieving medication.

Family caregivers' acceptance of death

The nurses noted that it could be difficult for the family caregivers to accept death in the last phase. The nurses had experienced different understandings of treatment choices among health personnel and family caregivers and differences among patients and family caregivers concerning future treatment. They observed that treatment limits were often not decided in advance. A common understanding between healthcare personnel and family caregivers is crucial in providing compassionate care. Sharing information about palliative treatment was highlighted as one way to promote a better understanding of the treatment. Communication with the family caregivers after the patient's death was viewed as crucial. The nurses mentioned bereavement conversations, but the offering of this kind of conversation differed between and within municipalities. The nurses spoke about individual needs for bereavement conversations and mentioned that family caregivers often wanted to speak with the health personnel who had been present at the time of the patient's death. The nurses believed everyone would benefit from such conversations.

6.1.3 Study III

Tarberg AS, Thronæs M, Landstad BJ, Kvangarsnes M, Hole T. "Physicians' perceptions of patient participation and involvement of family caregivers in the palliative care pathway" *Health Expectation*. https://doi.org/10.1111/hex.13551 (Tarberg et al., 2022).

This study aimed to explore physicians' perceptions of patient participation and family caregivers' involvement in the different phases of palliative care. Their perceptions were interpreted in relation to three themes following the different phases of the palliative pathway: 1) doing good for the patients and the family caregivers, 2) autonomy and shared decision-making, and 3) family involvement in the terminal phase.

To do good for the patients and the family caregivers

The physicians described the early phase as emotionally difficult for the patients and family caregivers, and they tried to form a close therapeutic relationship with them during this period. The desire to do good for the patients and the family caregivers was highlighted. For example, it was important to provide information and meet the patients’ and family caregivers’ emotional needs. The physicians were concerned with listening to and creating openness in the pathway. Ideally, they preferred to give information to the patients and caregivers simultaneously. The physicians wanted to do what was best for the patients, and this was in their opinion sometimes to decide upon treatment choices on behalf of the patients. This seemed to present an ethical dilemma for the physicians—balancing between deciding what was in the best interest of the patient and promoting shared decision-making with the patient and the family. Physicians viewing it as important to establish therapeutic relationships with the patient and family caregivers. Elements of this phase included creating security for patients and family caregivers, planning regarding what could lie ahead, and balancing family caregivers’ concerns and management abilities. The physicians considered it crucial for patients and family caregivers to receive information concerning who would be responsible for the treatment. Moving from curative to palliative treatment could sometimes be difficult when the patients’ understanding of the treatment was different from that of the physicians. The physicians described it as presenting an ethical dilemma when the patient did not want the family caregivers to receive information about their condition.

Autonomy and shared decision-making

The middle phase was described as an emotionally calmer period focusing on patient autonomy, shared decision-making, and family caregivers’ involvement in discussing future challenges and decisions. In the middle phase, necessary information had been given, and trust toward health personnel was usually established. Still, it seemed to present an ethical challenge to fulfil responsibilities and create a sense of security in the treatment in light of constant changes in health personnel.

The physicians believed that ACP was a good tool to promote conversations with patients and family caregivers about the pathway, expectations for the future, and their thoughts regarding participation. The GPs and primary care palliative teams, in particular, talked about making care plans. Still, there was a lack of reflection about involving family caregivers in the ACP conversation. The physicians described challenges in securing continuity of care and emphasised building trust. They highlighted family caregivers as crucial resources, especially just before and during the terminal phase. They perceived that family caregivers had differing resources and worried about the adequacy of resources available to care for the patients. Further, they remarked that family caregivers often mobilised more resources than expected.

The physicians highlighted the involvement of family caregivers throughout the pathway and noted that this had become more common in recent years.

Family involvement in the terminal phase

In the last phase, the family maintained the patient's autonomy, and the physicians depended on family caregivers as a link in promoting the patient's best interests. It was crucial to clarify with patients early in the pathway that the physicians would contact family caregivers when patients themselves no longer could make decisions. Regular follow-up with family caregivers was necessary for this phase, especially regarding symptom relief. The physicians stated that patients could find relief in letting family caregivers play a more prominent role in caring for them through the dying process. They thought that family caregivers' involvement throughout the terminal phase relieved their grieving process and prevented ethical conflicts, as their involvement promoted that they felt seen, heard, and respected throughout the pathway. The physicians provided information to the family caregivers concerning the post-death period, which was seen as essential in supporting the mourning process. Giving common information and communication to patients and family caregivers through all phases of the palliative pathway was seen as essential to supporting the family caregivers' morning process. The physicians highlighted bereavement conversations as a positive approach to summarise the experience and possibly avoid prolonged trauma.

6.2 Synthesis of the findings

The three studies illuminate the complex relation of patient participation, family involvement, and compassionate care in the different phases of the palliative care pathway. The intention behind interviewing family caregivers and healthcare personnel was to explore different perspectives on the palliative care pathway.

To synthesis the findings from the parts to form a whole, we have performed new analyses that include the findings from all three studies (Appendix 2). The themes are inspired by the theoretical perspectives we have adopted that best synthesis the findings. We used different theoretical perspectives in interpreting the themes in the three studies, but the theoretical perspectives have common features that contribute to a more comprehensive understanding of participation and care.

In analysing the main findings, we have emphasised differences and similarities using the themes and subthemes within the coding tree of each study (Appendix 2) to create a synthesis, and the themes are summarised in Table 5.

The findings showed different levels of patient participation and family involvement within the different phases of the palliative pathway. It appears that family caregivers, nurses, and physicians shared a similar view of the importance of participation and involvement throughout the pathway. However, the primary care nurses felt that they were included too late and thus were unable to contribute to patient participation and family involvement early in the pathway. In Study II, compassionate care was highlighted as a crucial component of palliative care, and one that promotes participation and involvement.

Family caregivers expressed feeling a low degree of involvement in all phases of the palliative process. The results indicate that family caregivers were little empowered to participate in care and treatment decisions, and this lack of participation is at odds with the level of responsibility they experience. The nurses in the study planned palliative care in a compassionate way. They spoke a great deal about planning in the patients' best interests. However, for them, it seemed more challenging to include family caregivers in this process, and family caregivers were given a less distinct role when planning care and treatment. The physicians strived to provide the patients with autonomy and simultaneously do well for the family caregivers and involve them throughout the pathway. The physicians also experienced this balancing act as ethically challenging and highlighted competent communication as essential.

Table 5. Synthesis of findings in the three studies

Synthesis of findings	**Early involvement and professional decisions**	**Patient-centred care and lack of acknowledgement of family caregivers**	**Family caregivers' involvement in care and acceptance of death**
Family caregivers	Limited involvement in the early phase	Emphasis on patient-centred care in the middle phase	Lack of preparation for the dying phase
Nurses	Information and dialogue in the early phase	Creating a space for dying	Family caregivers' acceptance of death
Physicians	To do good for patients and family caregivers	Autonomy and shared decision-making	Family involvement in the terminal phase

6.2.1 Early involvement and professional decisions

The nurses highlighted the importance of early dialogue between patients, family caregivers, and healthcare personnel, and they noted that early involvement increased their ability to provide compassionate care. Interdisciplinary collaboration between specialist healthcare services and primary healthcare was considered important to improve compassionate care.

Family caregivers expressed that although they were well informed about the patient's diagnosis, their involvement in defining problems and challenges regarding the care of the patient was limited. Family caregivers conveyed that the patients and their families could have different needs and wished for separate conversations with health personnel. Some family caregivers expressed that requesting a one-to-one conversation while the patient was present was a challenge. Furthermore, the information they received seemed to depend on the questions they asked. They wanted more information about how the disease would develop and what to expect in the different phases of the pathway.

The physicians described the early phase as demanding for patients and family caregivers, and they saw it as important to establish a close therapeutic relationship with patients and their family caregivers. They remarked that treatment choices often were made by the physician because the patient and family caregivers were in a vulnerable situation and did not possess the knowledge to understand the consequences of the treatment choices. The physicians were concerned with doing what they thought would benefit the patient and family caregivers in treatment decisions. They highlighted compassion, including information and dialogue, as essential in the transition from curative to palliative treatment. Creating security for patients and family caregivers was also important for the physicians in the study.

The physicians' duty of confidentiality toward the patient was emphasised. Some patients did not want information to be passed on to their family caregivers, and this was experienced by physicians as presenting an ethical dilemma. The physicians noted that they sometimes urged patients to communicate the information to family caregivers based on their best interests.

6.2.2 Patient-centred care and lack of acknowledgement of family caregivers

The middle phase was characterised by patient-centred care and shared decision-making.

Health personnel conveyed that the second phase seemed to be a quiet period for patients and family caregivers, one in which patients and family caregivers were provided with security, predictability, and clarification. The nurse found it important to be aware of patients' and family caregivers' mental and physical needs. Both physicians and nurses described the middle phase as a phase in which the patients were at the centre of the planning of palliative care. Health personnel highlighted that it was important to create a space for dying and shared decision-making and noted that family caregivers were more involved in the care in this phase.

Family caregivers also described this phase as patient-centred, indicating that it was the patients' wishes and needs that were in focus and that the patients' wishes determined the help they received, including their preferences regarding staying at home. Several family caregivers described this as a very stressful phase; one in which their caregiving role overshadowed their role as a family member. The family caregivers mentioned that the patient's wishes and needs were taken seriously by the healthcare personnel both in the hospital and in primary care. However, they felt that their own needs as family caregivers were occasionally neglected, and they were generally not involved in the decision process.

Nurses described the challenge they sometimes experienced in this phase of balancing conflicts among patients and family caregivers, which could be an obstacle in creating a plan for what might lie ahead. Physicians also described conflicts of interest among patients and family caregivers as a challenge; they addressed this challenge by emphasising patient autonomy and explaining that advanced care planning was an important tool. It was crucial for the physicians that the patient decided who should be involved and provided with relevant information.

The physicians highlighted family caregivers as resources in palliative care and believed it was important to spend time with them and to be aware of their needs, especially as the terminal phase approached.

6.2.3 Family caregivers' involvement in care and acceptance of death

Family caregivers described this phase as challenging as most of them had not experienced death before, and they felt insecure about what would happen. They expressed that there was little information about the death process and all that it entails. While the patients were dying at home, some family caregivers felt alone with the responsibility and burden.

Nurses and physicians had a convergent view and spoke of the importance of providing information to both patients and family caregivers. The physicians noted that they attempted to transfer patients' participation to the family caregivers in this phase. The nurses indicated that family caregivers were often tired in this phase and providing information about treatment was essential to help them cope and understand what had been decided.

The physicians remarked that family caregivers became more involved in the terminal phase, and that family caregivers who were involved in the palliative process would endure a softer grieving process and feel more secure. According to the physicians, this involvement might lead to family caregivers declining the offer of bereavement conversations.

Family caregivers, nurses, and physicians all described bereavement conversations as important and contingent upon context and individual needs. Each group expressed the importance of bereavement conversations in cases with challenging death processes. Furthermore, all three studies showed that offers of bereavement conversations were unsystematic and depended upon local routines.

7 Discussion

In this chapter I first discuss the overreaching themes of the findings, and then I discuss the methodology, the methods, reflexivity, trustworthiness, theoretical perspectives, and my role as researcher.

7.1 Discussion of findings

The purpose of this study was to obtain knowledge about patient participation, family involvement, and compassionate care as experienced by family caregivers and health personnel in the different phases of the palliative cancer care pathway. The study provides new and important knowledge about these topics. Through the lens of different theoretical perspectives new aspects of participation and care in the palliative pathway are highlighted.

The studies shows that participation and involvement are contextual. This is highlighted in the three themes that synthesise the findings of the three studies: 1) Early involvement and professional decisions, 2) patient-centred care and lack of acknowledgment of family caregivers, and 3) family caregivers' involvement in care and acceptance of death. The phases are fluid, and some findings are consistent across the various phases. However, studying patient participation, family caregivers' involvement, and compassionate care in relation to the various phases has helped to bring out the contextual aspects of these phenomena. I will focus on particularly interesting findings in the studies, and the discussion is structured according to the various phases of the pathway.

7.1.1 The first phase

Some of the physicians in our study conveyed that patients and family caregivers could be in need of being shielded from decisions about treatment choices, or to receive information gradually over a period of time. Beauchamp and Childress (2019) talk of soft paternalism, and physicians' actions of shielding the patient could be interpreted as a form of soft paternalism. But I do not view the physicians' actions as paternalistic, seeing the interviews as a whole. I interpret that the physicians intended to maximise benefits for their patients and their families in a crisis. In the context of a crisis, such as the early part of the palliative pathway, there could be a need to release information gradually over a period of time, as in the careful management of medical information (Beauchamp & Childress, 2019). Beauchamp and Childress (2019) use the word 'veracity' when transferring information in a timely, accurate, objective, and comprehensive way. Communication is complex, and physicians need to consider how much information a patient is able to receive (Beauchamp & Childress, 2019). This idea accords with Thompson's (Thompson et al., 2007; Thompson, 2007) notion that being in a crisis early in the pathway might indicate a reduced demand for participation, and that information needs to be delivered through emotional reciprocity. The difficulty in communicating information could lead to an ethical conflict for the physicians; a conflict between beneficence and respect for autonomy (Beauchamp & Childress, 2019).

Family caregivers' roles are twofold. Family caregivers often take on a great responsibility in caring for the patient while being, at the same time, emotionally related to the patient as close relatives. This double role requires that physicians inform family caregivers thoroughly about the trajectory of the illness while at the same time meeting the family caregivers' emotional needs (Saarinen, 2021). Compassionate communication is thus important to ensure beneficence for both the patients and their family caregivers (Beauchamp & Childress, 2019). Findings from our study of physicians show that emotional reciprocity, offering treatment choices, and creating security for the patient and family caregivers were highlighted in the first phase. These findings have similarities with the dimensions of compassionate care: noticing, feeling, and responding (Kanov et al., 2004).

A review by Phillips et al. (2019) found a substantial gap in the acknowledgement and documentation of patients' individual needs. This included the level of information provided, how the patient wanted to participate in the decision-making, and the extent to which they wanted their families and associated nurses to participate (Philips et al., 2019). The physicians and the nurses in the studies highlighted the significance of advanced care planning. Research has shown that making plans for the palliative pathway that respect patients' wishes and needs and patients' and family caregivers' preferences for end-of-life care is essential to the organisation of palliative care (Kishino et al., 2022; NOU 2017:16, 2017). The nurses interviewed highlighted planning for what lay ahead, early involvement, and introducing ACP as important factors in securing high-quality palliative care and the participation of patients and family caregivers. Previous research has indicated that ACP has a positive effect on the quality of end-of-life care, and that patients feel supported when provided ACP (Brinkman-Stoppelenburg et al., 2014; Hui et al., 2018; Khan et al., 2014; Lin et al., 2019; Sedini et al., 2021). I argue that compassionate care and patients' and family caregivers' participation may be strengthened by working through ACP. Early dialogue with patient and family caregivers may provide a palliative pathway in accordance with their values and preferences. According to Kuosmanen et al. (2021), the primary responsibility in planning lies with the healthcare personnel and the organisational level within palliative care.

In report 26 (Helse- og omsorgsdepartementet, 2015), it was pointed out that ‘patients, users, and family caregivers shall be as important as professionals and politicians in change work’. In the NOU report ‘On life and death’ (NOU 2017:16, 2017), health personnel, such as GPs, home nurses, cancer coordinators, and palliative care team members, are referred to as critical players, and family caregivers are mentioned as an important resource (NOU 2017:16, 2017). Although the NOU report (NOU 2017:16, 2017) emphasises that family caregivers should be involved early in the process, the report does not discuss practical approaches to how this can be achieved. The NOU report uses words like ‘support’, ‘facilitation’, ‘guidance’, ‘relief’, and ‘good interaction’ and indicates that the health service must provide general information, advice, and guidance (NOU 2017:16, 2017). Research shows that barriers and facilitators in promoting better and safer care often depend on physicians' perceived time available, organisational support, and individual physicians and patients (Fine et al., 2010; Schildmeijer et al., 2018). It seems that there is a need for municipalities and specialist healthcare services to develop more concrete guidelines and measures for how the intentions expressed in the health policy documents are to be realised. From my point of view, contextual, organisational, and individual factors are essential for how health personnel can meet the needs of patients and family caregivers in participation, involvement, and compassionate care.

7.1.2 The middle phase

The three studies show that the middle phase is characterised by patient-centred care, but without attending the needs of family caregivers as part of truly patient-centred care (Lamore et al., 2017; Pottle et al., 2017; Rakic et al., 2018). The family caregivers experienced that their needs for support were neglected. This is an interesting finding that may give new insight into the challenges family caregivers experience in the pathway, challenges that may have been overlooked in policy documents and past research. Family caregivers are given greater responsibility when the goal is to achieve more home deaths (Helse- og omsorgsdepartementet, 2009; NOU 2017:16, 2017; World Health Organization, 2016-2020). According to Naoki et al. (2018) and Pottle et al. (2017), family caregivers may experience great strain during the palliative process, and their own needs and desires are often not attended. Everyday life can become much more demanding for them, and some family caregivers feel that they have taken on too much responsibility, more than they had anticipated (Rakic et al., 2018). Patient-centred care is often promoted in a positive way without acknowledging the family caregivers' need for involvement (Lund et al., 2015; Pop et al., 2022; Røen, 2022; Wang et al., 2018; Woodman et al., 2016). Moreover, in the WHO definition (World Health Organization, 2020) and in Kaasa et al. (2018) family involvement is highlighted as an important part of patient-centred care. Kristvik (2015) emphasises that family caregivers play a crucial role in safeguarding patients' identity, interests, and values together with managing the continuity of care and practical nursing tasks (Kristvik, 2015). My thoughts about this finding is that it may be healthcare personnel's understanding of family caregivers' role in the pathway and caring process that has led to this neglect. If the patient's rights are at the forefront of consideration, and the care given is patient-centred, the role of family caregivers might become vague, even though there should be no reason for this conflict related to the content of patient-centred care (Catalyst, 2017; Gerteis, 1993).

In our study of family caregivers, the need to be involved is an important finding. Furthermore, in our studies of the experiences of physicians and nurses, the early and long-term involvement of family caregivers is emphasised. Research shows that to improve family caregivers' quality of life, it is essential for them to be involved in planning and treatment decisions and to have emotional and social support (Pop et al., 2022). This is in accordance with Kristvik as she highlights that a physician who gives information to a patient without involving the family caregiver, needs be aware that an actor (family caregiver) who is deeply involved might be bypassed (Kristvik, 2015).

Several family caregivers in our study expressed a desire to speak with health personnel about the expected disease trajectory, and how it would affect their role as caregivers and the family situation. They wanted more information on how the disease would develop and what to expect in the different phases of the illness. The caregivers' desire for information was not always congruent with that of the patient, and these differences hindered family caregivers from entering into a dialogue with healthcare providers and to obtain the information they needed to be prepared for the different phases of the palliative pathway. Several family caregivers also expressed ambivalence about the patient's wish to die at home. Research indicates that family caregivers seldom ask for support from physicians (Parmar et al., 2020). An Australian study revealed a gap between guidelines and family caregivers' experiences of emotional and psychological support in palliative care (Aoun et al., 2017). Similarly, our study found a gap between the experiences projected in policy documents (NOU 2017:16, 2017) and family caregivers' actual experiences. The family caregivers in our study experienced a lack of information and social support in the middle phase. This may be understood in light of that healthcare personnel may not recognise family caregivers' role in the teamwork involved in palliative care. The lack of recognition of family caregivers’ role in care is also supported by previous research (Landstad et al., 2020), and is not in accordance with the content of patient-centred care as defined in the literature (Catalyst, 2017; Gerteis, 1993; Håkansson Eklund et al., 2019).

The physicians in our study highlighted family caregivers as central resources in palliative care, and they believed it was vital to spend time with them, especially as the terminal phase approached. It was also essential to be aware of family caregivers’ resources. In our study, the family caregivers played both a central and distant role. The family caregivers were central so that patients could be at home in their final days. Concurrently, it seemed like family caregivers played a distant role without having their own needs and rights addressed. There seems to be no integrated family caregiver role in the palliative pathway. Instruments to identify carers struggling with caring for someone dying at home have been developed. One such resource is the Carers Alert Thermometer (CAT), an instrument of 10 questions. Research on the implementation of the CAT indicates that it enables discussions about issues affecting family caregivers and also seems to be valuable in identifying elements the family caregivers feel to be burdensome (Knighting et al., 2016; Knighting et al., 2015). In addition, the study found that the tool was acknowledged by health personnel as a clear indicator of family carers’ needs. A second instrument is the Carer Support Needs Assessment Tool (CSNAT), with 15 questions developed to examine broad areas of family caregivers’ support needs, enabling carers and healthcare personnel to discuss the carers’ needs for support (Aoun et al., 2015; Ewing et al., 2013; Ewing & Grande, 2013). The instrument has been evaluated in Sweden and found relevant and useful in identifying the support needs of family caregivers within palliative care (Alvariza et al., 2018). The Norwegian Ministry of Health and Care Services also recommend the use of the CSNAT in Norway (NOU 2017:16, 2017). However, none of the health personnel interviewed in our studies referred to the use of either of these instruments.

7.1.3 The terminal phase

The family caregivers in our study expressed that they felt alone with the responsibilities and the burden of caring for the patient. Research highlights that it is complicated to balance the burden of care with family caregivers' ability to cope (Andershed, 2006; Knighting et al., 2015; Proot et al., 2003). The family caregivers in our study called for more concrete information about the process of dying. The family caregivers described the terminal phase as challenging and felt insecure about what would happen to the patient. They stressed that they received little information about the death process and all that it entails. This finding is in accordance with earlier studies indicating that health professionals underestimate family caregivers' needs for information and do not recognise the need to use understandable language to explain the palliative process, especially in the terminal phase (Collins et al., 2017; Knighting et al., 2015; Røen et al., 2018). Previous studies have likewise highlighted carers' desire for more information about what to expect. Family caregivers need healthcare professionals to clearly explain the dying process (Dose et al., 2015; Pop et al., 2022). Involvement in the care of the patient might strengthen the family caregivers' resources following patients' pathways (Lamore et al., 2017; Lund et al., 2015). Lund et al. (2015) found it warranted to focus more on the involvement of family caregivers, suggesting that this should include taking an interest in what family caregivers are feeling. In a review, Lamore et al. (2017) found that most of the existing literature described social support for family caregivers but that less was known about their role as intermediaries and collaborators.

The physicians in our study highlighted that family caregivers often were strongly involved in decision-making and care in the terminal phase, and that the patient's autonomy could be maintained by family caregivers. The physicians and nurses we interviewed anticipated that family caregivers involved in the palliative process would endure a softer grieving process and would feel more secure in the terminal and bereavement phases. The literature indicates that family caregivers take on a new and demanding role in safeguarding the patient's interests. Communication between family caregivers and healthcare personnel is essential to achieve cooperation. Family caregivers, patients, and nurses may be at different stages in accepting death (Wilson et al., 2014). It is important that healthcare personnel and family caregivers have a common understanding of how they can best support the patient in the dying process. How family caregivers experience the dying process will impact their grieving process. Health personnel have to prepare families for the emotions they are likely to meet in the grieving process (Kutner & Kilbourn, 2009). Further, conflict may arise when patients conceal information about their medication or misunderstand and feel suspicious (Lund et al., 2015; Wilson et al., 2014).

The family caregivers, nurses, and physicians in our studies described bereavement conversations as important and contingent upon context and individual needs. The studies emphasised the importance of bereavement conversations in cases with a challenging death process. Further, all three studies showed that offers of bereavement conversations were unsystematic and depended upon local routines. Follow up of the bereaved is an element of WHO guidelines (World Health Organization, 2016) that seems not to be followed systematically in Norway. Ensuring a support system during bereavement is vital for the nursing role, and little is known about how to provide the best compassionate care and practical nursing for the family caregivers (Holtslander, 2007). Nurses must be competent and have the courage to take charge in the bereavement care (Johnson, 2015). In our study it emerged that family caregivers mainly wanted to talk to health personnel who were present during the last hours of the patient's life and that bereaved conversations should be organised and offered to all bereaved.

7.2 Methodological discussion

We designed the studies to obtain knowledge about patient participation, family involvement, and compassionate care as experienced by family caregivers and health personnel in the different phases of the palliative cancer care pathway.

In our project, we chose qualitative individual interviews and focus groups as methods of collecting data. These approaches yielded complementary empirical data capable of answering the research questions addressed. A variety of qualitative approaches may provide a complementary understanding (Denzin & Lincoln, 2018), and was intended to give a broader insight into health personnel and family caregivers' perception and experiences of the different phases of the palliative pathway. Family caregivers have a central role, and giving them a clear voice was important.

As a researcher, I am responsible for making the data-gathering and interpretation as transparent as possible to ensure the study's trustworthiness. Throughout this research process, I have emphasised reflexivity as fundamental. We are aware that the stories told do not reflect the whole truth but rather offer a version of events as seen from the participants' perspective. Different methods—for example, observation—could have yielded different results and perspectives.

It is, however, important to consider that the information obtained from the different sources is 'indirect' information related to patient participation as it is seen from the perspective of healthcare personnel and family caregivers and not the patients. Patients themselves, who would be the primary source of information regarding how clinical practice regarding patient participation is experienced throughout the patient pathway, were not interviewed. Although this decision might be seen as a weakness of the study, our intention was to seek experience with the whole pathway from different perspectives, and this also included the follow-up of the bereaved.

7.2.1 Reflexivity

Reflexivity relates to the awareness of the researchers' position, the methodological choices, and changes made in the process. In qualitative studies, the researcher is the primary research instrument. Thus, there is a need to identify our backgrounds, values, assumptions, and biases to allow the reader to assess how the interpretation of the results might have been influenced (Creswell, 2014; Malterud, 2017). During the data collection phase, the health personnel in our studies willingly shared their experiences and the family caregivers' their personal histories, and this provided varied descriptions which contributed to the rich data we assembled and the knowledge of palliative care that data yielded.

In this research project, I have acknowledged my background as an oncology nurse and been aware that this background might have affected the research process. The discussion with my supervisors was most valuable in this process. However, my background as an oncology nurse was probably also a strength due to my experience in communicating with family caregivers, nurses, and physicians.

7.2.2 Trustworthiness

There are different approaches to evaluating the quality of qualitative research (Brinkmann & Kvale, 2015; Malterud, 2017; Patton, 2015). Lincoln and Guba (1985) have suggested the term 'trustworthiness', which encompasses the following criteria: credibility, dependability, transferability, confirmability, and additional authenticity. To promote trustworthiness, I relied on the terms suggested by Lincoln and Guba (1985) and self-scrutinising questions (Polit & Beck, 2012). Moreover, I have emphasized critical thinking and self-reflection concerning the decisions made during the research process to ground my interpretations of the data.

Furthermore, I have emphasized transparency concerning the many choices made throughout the research process and have tried to describe them thoroughly in the separate articles and in this thesis. I continuously discussed the study design, findings, and interpretations with my supervisors, thus ensuring different perspectives and understandings of the phenomena studied.

Credibility refers to confidence and trust concerning the interpreted data (Polit & Beck, 2012). I focused on employing proper relations between the participants' stories and the research group's interpretations. In addition, a thorough reflection on my pre-understandings and an effort to build study transparency into all phases of this research project were essential. To increase credibility, we described the participants' demographic data and constructed a coding tree of the themes, sub-themes, and quotations. Quotations from the participants were used to underpin their accounts, support claims, and evoke emotions. The participants were given an immediate opportunity to correct or make a reaction of what had been said after each interview (Lincoln & Guba, 1985).

Additionally, to build credibility, we focused on representing the experiences and the context of the participants. I worked to create an open atmosphere during the interviews, summing up the conversation and giving participants the opportunity to clarify or correct their statements. In addition, credibility was strengthened by allowing the participants to provide feedback on the findings. In each study, participants could provide feedback at the end of each interview but not on the interpretations (Lincoln & Guba, 1985). Moreover, as a research group, we reflected upon our pre-understanding and various backgrounds and continuously focused on the research questions throughout the research process. This reflection made us aware of our varying expectations and helped us to avoid drawing premature conclusions during data interpretation.

Transferability it is important to provide sufficient descriptive data for the reader to evaluate the transferability in relation to other contexts. To ensure transferability in relation to the context in qualitative studies it is essential to describe the connection between the result and the collected data (Polit & Beck, 2017). I focused on writing thick descriptions and providing as many details as possible to let the readers see connections between our findings and the context. For example, the findings of Studies I, II, and III are presented with quotations from family caregivers, nurses in primary care, and physicians, respectively to demonstrate the connection between the data and the results of each study. Moreover, the results of the three studies are synthesised and interpreted as a whole in the thesis. I acknowledge that the reader can apply the findings of this research to new situations (Brinkmann & Kvale, 2015), and we have tried to fulfil our responsibility to provide sufficiently descriptive data to enable the reader to evaluate transferability to other contexts (Polit & Beck, 2012).

Dependability relates to whether the participants' stories are credible and consistent over time when repeated under different conditions (Lincoln & Guba, 1985). This means that the reader will be able to evaluate the analysis in following the decision-making process of our research (Holloway & Wheeler, 2010). To increase dependability we have focused on transparent research documentation, and to describe the findings consistently and accurately (Lincoln & Guba, 1985).We have described the research context, providing demographic data and inclusion criteria. We acknowledge that the results of this research cannot be replicated, but the research can be repeated. To increase study dependability, thick descriptions of the participants' experiences and perceptions have been provided. I also returned to the transcript several times throughout the analysis process. In the process of data interpretation, we created transparency by using coding trees to demonstrate how specific themes and sub-themes were formulated within citations of each sub-theme. The research group repeatedly discussed the initial formulation of the study results—as, for example, when findings contradicted our pre-understanding and there was a need to consider alternative interpretations.

Confirmability concerns establishing data that represents the same information as provided by the informants. The enquirer must refrain from inventing data for the study to achieve confirmability (Polit & Beck, 2012). Confirmability was established by representing the participants' data, constructing a coding tree, and including quotations reflecting the participants' voices rather than the researchers' perspectives. We strived to establish data that accurately represented the information provided by the informants. There is always the potential risk of incongruity between the researchers' and the participants' voices (Lincoln & Guba, 1985; Polit & Beck, 2012). We held several meetings to discuss the adequacy of the interpretation process by which we developed different themes and sub-themes. To strengthen the confirmability of the data, we also reflected upon our pre-understanding to move away from our preconceptions and be open to new horizons of understanding (Gadamer, 1989). Subsequently, the findings and conclusion followed the research aims and research questions (Holloway & Wheeler, 2010).

Authenticity is true reporting of the participants stories which involves fairness, understanding the context of their social world, understand, empower and let the participants make decisions (Holloway & Wheeler, 2010). Lincoln and Guba (1985) highlight that empathy between the researcher and participants might increase the possibility of collecting richer and more detailed data with the intention of producing more credible and trustworthy findings and a more substantial authenticity in presenting the participants' viewpoints (Lincoln & Guba, 1985). In our research project, we wanted to explore the experiences and perceptions of family caregivers, nurses, and physicians. To achieve authenticity, we have emphasized to represent the participants and let their voices be heard. It was essential to formulate their experiences and perceptions as they were expressed, helping the reader to understand the participants' experiences. In this process we also focused on establishing self-reflectiveness within the research group.

Throughout the research process, we emphasised a reflexive approach, developing our understanding through the initial interpretation of each interview text and interpreting our findings through our chosen theoretical lenses. Furthermore, we used several theoretical perspectives to gain a broader understanding of the informants' experiences.

We also used the COREQ checklist (Tong et al., 2007) to guide transparency. However, Williams et al. (2020) argue that a debate still remains on how and whether to appraise qualitative research critically in terms of trustworthiness. Moreover, checklists might be a blunt and arguably ineffective tool as they focus on objectively assessing quality in a positivistic manner (Tod et al., 2021; Williams et al., 2020). Williams et al. emphasise the need for a more robust qualitative approach that encompasses both the design and different methodological approaches (Williams et al., 2020). I used COREQ (Tong et al., 2007) as an evaluation checklist to achieve a transparent presentation of all three studies. Using this checklist helped me critically and systematically reflect on my approach in all parts of the research process, including the need for transferability (Malterud, 2017). However, I did not use the checklist rigidly but rather tried to engage continually with an open-ended list of criteria for judging the studies (Tod et al., 2021).

7.2.3 The recruitment processes

A varied sample was recruited in all three studies, and this contributed to a deeper understanding of patient participation, family involvement, and compassionate care among patients and family caregivers. In recruiting participants, purposive sampling was conducted. We wanted to include men and women of different ages from rural municipalities and larger towns to ensure a diverse sample of palliative care experiences (Patton, 2015). However, a possible weakness of the sample collection is that participants were suggested by the contact person. We do not know the contact person's approach to recruit participants. The contact person used the criteria as they were perceived, but we do not know if there were more suitable candidates.

7.2.4 Data collection

When interviewing, it is important to remember that the situation is context-bound. It cannot be known how honest interviewees want to be, and they may be guided by social realities and individual interests (Alvesson, 2003). For example, one of the family caregiver interviewees expressed that she had a specific reason for participating: she wanted to share that she had thought that the physicians in the hospital were responsible for the patient's medical treatment but learned after the patient's death that it had been the GP who held responsibility. During the interviews, I tried to be open and relaxed to encourage the participants to reflect openly and honestly.

Individual interviews were chosen because we wanted to explore the family caregivers' stories and views on participation and involvement (Chase, 2018; Holloway & Freshwater, 2007). It seemed appropriate to conduct individual interviews with the family caregivers as these are vulnerable groups, and it would have been difficult to organise focus groups across municipalities. Focus groups might, however, have created different dynamics that would have caused other experiences to emerge.

We chose focus groups to collect data from the nurses to promote dynamic interactions among the participants. We recognise that interpersonal constellations could have inhibited nurses from elaborating potentially controversial views, and that individual interviews could have allowed a more in-depth exploration of the topics (Malterud, 2012). As the focus groups engaged, the sharing came easily, and the stories were rich and detailed. Some of the participants were a bit quiet. As a moderator, I challenged them by asking questions to engage all participants.

There were only three participants in one of the focus groups, which may have been a weakness in that there was less input in this discussion compared to the other groups (Malterud, 2012). However, at the same time, we felt that this group of three participants had excellent discussions and gave us rich material.

When planning to interview the physicians, we discussed how best to collect data. We found it challenging to arrange focus groups because the physicians worked in different health arenas and in different geographic areas. The COVID-19 pandemic increased this difficulty. The individual interviews with the physicians provided rich material, and video interviews were not an obstacle to this.

The 34 health personnel represented a purposive sample as they possessed different educational backgrounds, and each was experienced in working with patients and family caregivers in the palliative phases. According to Yardley (2000), having too many participants could hinder the in-depth analysis. Nevertheless, it might be argued that the number of participants was relatively small, and that increasing the number of participants might have given more detailed descriptions and richer variation. On the other hand, the saturation of the material was considered explicitly in each study to lower this risk.

7.2.5 Analysis

The qualitative analyses aimed to make sense of the data by looking for patterns, identifying themes, answering the research questions, and presenting findings (Patton, 2015). We have focused on describing the qualitative analyses systematically in all three studies. The findings are the participants' experiences as interpreted by the research group, and we acknowledge that other interpretations by other research groups and readers may be possible. The research group consisted of experienced researchers who contributed to each stage of the research process. The use of different theoretical lenses may have provided a wider frame of interpretation of the studied phenomena (Patton, 2015). Although other theoretical perspectives could have provided additional focus and nuances, we believe that the theoretical perspectives used are relevant to illuminate the research questions. Some of the main findings in the studies, such as the early involvement of the family caregivers and patient-centred care in the middle phase, were highlighted in all three studies by the different data providers.

In the analysis of Study I, we focused on each narrative, paying attention to both the content and the narration as well as the structure and trying to pay attention to what was unsaid and unsayable (Josselson, 2011). At the same time, my background as an oncological nurse in primary care was a part of my pre-understanding. The palliative pathway seemed to correspond well to the structure of narratives, having a beginning, a middle, and an end (Holloway & Freshwater, 2007).

A hermeneutic approach was chosen for the studies involving nurses and physicians, providing an understanding based on an interpretation of the meaning of what had been told. Participation is contextual, and a hermeneutic approach was considered appropriate for interpreting the underlying meaning. Our pre-understanding and horizon were challenged following hermeneutics, and together in the research group we achieved a new understanding. Being an oncological nurse working in primary care was a part of my pre-understanding, and this might have been valuable for interpreting what the healthcare professionals conveyed.

According to Flick (2018), thematic analysis as described by Brown and Clark (2013), should include other approaches. Thematic analysis that stands alone has been criticised for not explicitly conveying the underlying thoughts of analyses. In Study III, we have combined thematic analyses with the hermeneutic approach to yield a more comprehensive analysis of the interviews.

7.3 Discussion of theoretical frameworks

Various theoretical perspectives were used in the three studies. The perspectives were Thompson’s taxonomy of involvement and the integrative approach to patient involvement and participation, compassionate care, and the four principles of biomedical ethics. The use of theory may raise the discussion and allow for a new and deeper understanding of the findings (Malterud, 2017). According to Patton (2015), theoretical frameworks provide different theoretical lenses. According to Creswell (2014) and Tong (2007), the theoretical perspective is a lens to focus on the phenomena studied. In our view, the use of three various perspectives offered a more nuanced view of participation and care related to patients and family caregivers.

Choosing various theoretical perspectives for the different studies could be seen as a logical weakness. However, I argue that it has been a strength. The various theoretical perspectives provided complementary understandings of how participation is experienced and how it appears in clinical practice. The research group discussed the theoretical perspectives repeatedly, and our view is that the three theoretical perspectives complement each other related to participation and involvement although each theoretical perspective focuses on a different part of patient participation and family involvement.

7.3.1 Thompsons theoretical framework

Thompson's (2007; 2007) theoretical perspective on involvement was used in Studies I and III. This approach was valuable in identifying and highlighting patterns of involvement in the various phases. Moreover, it revealed that patient participation and family involvement varied in the different phases of the palliative pathway. The research questions helped to focus the analysis. I might have chosen other theoretical perspectives. However, that might have required different research questions, and possibly a different study design. Choosing another theoretical framework than Thompson's would have influenced the analyses and could have given other findings.

Though this theory was developed for patients, the research group found this perspective also suitable for analysing family caregivers' involvement. Moreover, application of the theory in research on family caregivers has been performed in previous studies (Aasen et al., 2012).

Thompson builds his theoretical approach of involvement upon Arnstein's hierarchical ladder (1969). This hierarchical ladder has been criticised by theorists as Tritter (2009) who claims that viewing participation and involvement as a hierarchy might lead to less involvement. Furthermore, Tritter argues that it does not engage with the complexity and nuances of the patients' and the public's involvement. Others have criticised the lack of highlighting frame factors in the model (Bårdsgjerde, 2022).

7.3.2 Compassionate care

In the interviews with the nurses, we saw that compassionate care could be a valuable concept for analysing new findings about care and participation in the data material. In choosing compassionate care as the theoretical perspective in Study II, the research group discussed several theoretical approaches. The choice of different theoretical perspectives for each of the three studies has given the thesis richer and more nuanced findings about care, patient participation, and involvement of family caregivers. It has been more challenging than using the same theoretical perspective in all three. Nevertheless, we saw this as a strength that led to a richer and more complex picture of the subjects of investigation

Working with the analysis, the importance of compassion within palliative care became more apparent. Larkin (2016) writes that genuine compassion is expressed through the highest level of clinical practice and addresses the complexity of individual needs in palliative care systems. In our study, we understood compassionate care as comprising three dimensions: noticing, feeling, and responding. These dimensions demand action: for example when visiting patients, nurses must notice, feel, and respond. This idea led us to decide that compassionate care was appropriate as a theoretical perspective for this study. In my understanding, compassionate care is an action, and is necessary to promote participation with patients and family caregivers in palliative care. It is worth noting that 'pallia' in Latin means to cherish and protect. In our work with compassionate care, we acknowledged that compassionate care was contextual. Information and dialogue were essential to compassionate care in the palliative pathway's first phase. Creating a space for dying was influential in the middle phase. Working with family caregivers' acceptance of death was emphasised in the last phase.

Compassionate care was a central part of palliative care and participation in the study. Compassionate care might include early involvement in practice, making a plan (ACP), patient-centred care, including the family caregiver in planning terminal care, and creating a space for dying. Compassionate care can be considered a prerequisite for participation and involvement for patient and family caregivers. Still, the study showed a missing part in compassionate care in the lack of early involvement of family caregivers as central participants. Patient-centred care might lead to less compassionate care for the family caregivers because the patients' needs are often prioritised.

The choice of Compassionate care as a framework in study II was thus valuable for gaining knowledge about what nurses experienced as good quality in palliative care in different phases of the course. It became clear that patient participation and compassionate care have common features in care in practice. The importance of emphasizing patients' and family caregivers' preferences and meeting their emotional needs was apparent in all studies. Compassionate care was also essential for interpreting the theme "creating a space for dying." This theme can also be seen as a form of participation in palliative care where family caregivers were primarily involved and were allowed to take responsibility for the patient in the last phase of life. I realised that combining the theory of participation and compassionate care gave a richer and more practical understanding of palliative care as a source of knowledge for the field of practice. I have yet to find other studies that have included compassionate care in the different phases of the palliative pathway.

7.3.3 The four biomedical ethical principles

In Study III, the four biomedical ethical principles were used as an additional theoretical approach. After dividing the transcribed interviews into different phases, I focused on responses and their relation to the four ethical principles: autonomy, non-maleficence, beneficence, and justice. Focusing on these ethical perspectives helped me analyse and categorise the ethical challenges highlighted by the physicians regarding patient participation and family involvement. Using these principles gave insight into the underlying thoughts and reflections of the physicians concerning their choices.

In this study, Thompson’s (Thompson et al., 2007; Thompson, 2007) theoretical framework was used as a approach as we looked for participation and involvement among patients and family caregivers, but the four biomedical ethical principles supplied the dominant perspective.

The four biomedical principles are criticised in Europe (Holm, 1995; Rendtorff, 2002) for being local to American culture and not transferable to other cultures. However, Ebbessen et al. (2013) investigated whether the principles defined by Beauchamp and Childress are cross-cultural. They concluded that the principles were transferable to Danish biomedical practices. When we applied the theoretical framework articulated by Beauchamp and Childress, we saw the dilemma physicians faced in their efforts to both promote patient autonomy and do good for the family caregivers. We might not have seen this conflict as clearly if we had used only Thompson's taxonomy. Thus, these different theoretical perspectives enhanced the analyses.

7.4 Reflections on my role as a researcher

It is essential in the research process for me to acknowledge my position as a researcher and how it influences the work (Patton, 2015). In qualitative research, I, as the researcher, am deeply involved in the construction of the study (Patton, 2015). Being experienced in the study's contexts might lead to particular blindness's, but I have had an open-minded approach to liberate myself from taking ideas for granted (Alvesson, 2003). Following Alvesson, I applied theory to challenge my perspective. In close dialogue with my supervisors, I reflected on my role as a researcher and my formal field experiences throughout the research process (Råheim et al., 2016).

Alvesson (2003) writes about the difficulty of studying something one is heavily involved in. In addition, Alvesson argues that an insider is better positioned to reveal the 'true story' as they may have a more profound knowledge of the setting. He says that putting one's own life in perspective is essential, especially in research involving people in vulnerable situations and ethical dilemmas. I have carefully reflected on these matters. For example, I acknowledge that the interview situation with family caregivers reflected my work as a cancer coordinator. This reflection helped me position my role as a researcher. Further, using the narrative approach while interviewing the family caregivers was helpful as the approach focused on the interviewees' storytelling with limited interruptions from me. Gadamer (1989) notes that pre-understanding is unavoidable in the hermeneutic tradition and could be a precondition for understanding. While interviewing the nurses and physicians, the hermeneutic approach was helpful: being aware of the pre-understanding formed through my many years of work in the palliative field.

Many of the participants did know that I was a cancer nurse, according to the recruiter. I was aware that this could constitute a bias. However, I felt strong connections with the participants, and in my view, this connection prompted them to offer more detailed answers. Brinkman and Kvale (2015) associate this connection with the researcher's behaviour, integrity, knowledge, experience, honesty, and fairness and view these as crucial factors to promote richer material.

8 Conclusion

The research project has shown that health personnel exercise their roles in care and patient participation in different ways in the palliative pathway. The research provides new knowledge of patient participation, family involvement, and compassionate care of patients and family caregivers in the various phases of the palliative pathway. Our studies show that these phenomena are contextual, and we have described phenomena that characterise the various phases of the pathway. The findings indicate that dialogue and professional decisions characterised the first phase. Health personnel saw it as important that patient and family caregivers established early contact and got involved in planning the care. The middle phase was characterised by patient-centred care. However, the family caregivers shouldered a great responsibility to safeguard the patients' interests, and their own needs were addressed only to a lesser extent. In the terminal phase, family caregivers were often strongly involved in patient care and in fulfilling the patient's wishes and preferences. However, many of the family caregivers experienced a lack of involvement and acknowledgement during the palliative cancer care pathway. Compassionate communication between health professionals and patient and family caregivers was crucial throughout the palliative pathway. Bereavement conversations were highlighted by health personnel and family caregivers but were not offered systematically.

8.1 Implications for practice

Providing effective palliative care and improving the process of its delivery should be of interest to healthcare systems worldwide as the number of citizens requiring palliative care is expected to increase in the coming decades. The knowledge achieved in this research may be helpful for policymakers, health organisations, educational institutions, and healthcare personnel in their efforts to create better health services and promote better education in palliative care.

Some of the findings may be essential to improve the implementation of high-quality care in this demanding clinical setting. Based on our findings, we suggest a stronger focus in clinical practice on patient participation, family involvement, and compassionate care during the pathway. Moreover, how patient-centred care is delivered and how this might affect the family caregivers' need for involvement is important. The physicians in our study highlighted the early involvement of family caregivers, patient autonomy, individual needs, and beneficence for the patients and family caregivers. These physicians' experiences should be transferrable to health personnel in all kinds of palliative care, independent of the diagnosis or place of treatment. An ethical focus and compassionate care from physicians and nurses are important elements to strengthen participation, involvement, and care in the pathway. Earlier involvement of primary care nurses may strengthen planning, as well as including family caregivers in advance care planning.

Advance care planning is a tool involving patients and family caregivers in the planning of care and treatment and can enhance awareness in providing palliative care. Strengthening communication between patients, health personnel, and the healthcare system is necessary. It seems that there is a need to create concrete guidelines to safeguard the intentions of the health policy document on good palliative care. One suggestion is to introduce ACP early in the palliative pathway to promote patient participation and acknowledge family caregivers as a part of the team in planning and implementing ACP. Moreover, a common palliative care plan across primary and specialist health care might benefit patient participation and family involvement.

There should be more focus on family caregivers’ needs as they take on the responsibilities inherent in palliative care. Family caregivers are crucial in making it possible for patients to stay at home and receive home care. Therefore, their responsibilities should be recognised and taken seriously. Focusing on family caregivers’ need for early involvement and information on treatment, symptoms, and information on what could happen to the patient, especially when the patient is at home, is crucial. The recommendation from the Norwegian ministry of health care services concerning the use of the CSNAT should be considered in education and practice.

We suggest that the importance of bereavement conversations should be acknowledged, and they should be implemented in guidelines as a structured offer in all municipalities.

In Norway, the legal regulations at the policy level should discuss how to involve family caregivers as individuals with rights and needs taking part in the palliative pathway. An open debate concerning family caregivers' legal rights regarding information and participation should be welcomed.

8.2 Suggestions for future research

There is a need for more research on the largely invisible work family caregivers perform when patients remain at home in their final days, especially those family caregivers who are not seen as central participants in the pathway. Our findings indicate a need for more knowledge of health personnel's involvement of family caregivers in decisions concerning patients' treatment in the palliative pathway, especially when palliative care is received at home.

This thesis provides new insights into participation, involvement, and care for patients and family caregivers enduring the palliative pathway, and should be supplemented with research into patients' perspectives on participation and their family caregivers' involvement. Research into these matters would be valuable in expanding our understanding of this complex phenomenon. Furthermore, future research should focus on physicians and nurses facing ethical dilemmas in caring for both the patient and the family caregivers.

Our findings should also be supplemented with research into the perspectives of other groups receiving palliative care. Research focusing on the perspective of leaders and managers at an individual and a system level is also called for to expand our knowledge of this complex phenomenon.

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Appendices

Appendix 1: Interview guide for study I, study II, and study III

Appendix 2: Coding tree for study I, study II, and study III

Interview guides

Interview guide study I

Can you tell me how you experience the palliative care pathway?
How did you experience the information you received in different phases of the palliative care pathway (e.g., the early phase, middle phase, terminal phase, and bereavement phase)?
How do you experience being involved in the different phases of the palliative care pathway
Are there something else you want to add?

Interview guide study II

Can you tell me how you experience palliative care?
What is important when communicating with patients and family caregivers in different phases of the palliative pathway?
How do you wish to collaborate with family caregivers throughout the pathway?
What is important about the nature of the care offered in different phases of the palliative pathway?
What challenges and ethical dilemmas did you experience?
Are there something else you want to add?

Interview guide study III

Can you tell me how you experience palliative care?
How are patients and family caregivers involved in the different phases of the pathway?
What is important when communicating with patients and family caregivers in different phases of the palliative pathway?
What kind of information have you experienced as important to communicate?
How do you wish to collaborate with family caregivers throughout the pathway?
What is important about the nature of the care offered in different phases of the palliative pathway?
What challenges and ethical dilemmas did you experience?
Are there something else you want to add?

Coding tree study 1

Quotes	Subthemes	Theme
THEME 1 (early phase)		
"We felt well informed; The doctor told it like it was."	***Information-giving***	**Limited involvement in planning**
"We respected her desire not to be too informed about prognosis, but I would have liked to know a bit more."	***Family caregivers' independent need for information***	
"He decided. He let us know early on that he wanted to stay at home."	***The patient decided***	
THEME 2 (middle phase)		
"It was extremely tiring, because he didn`t want me to bring in a lot of people and make such a fuss; I was supposed to take care of everything and be in control all the time."	***Lack of family participation***	**Emphasis on patient-centred care in the middle phase**
"I should have asked for help much earlier. When I got help, I hadn`t slept for three months."	***Unclear transitions and responsibilities***	
"The family doctor communicated well with other health personnel who were involved in the treatment. Thus, we got important information that mother had short time to live."	***The need of involvement***	
THEME 3 (terminal phase)		
"I wondered whether she would be in a coma for days."	***Plan for the terminal phase***	**Lack of preparation for the dying phase**
"There was no contact until I contacted them."	***Lack of family involvement in planning***	
"It was good to be at the nursing home. The girls and I, we were all there and we were treated in a nice way. "	***Feeling of recognition***	
THEME 4 (bereavement)		
"I think it should have been a systematic process regarding this."	***Systematic approach***	**Lack of systematic follow- up after death**
"There are many questions I would like to ask about what happened in the last hours he lived."	***Need of support***	
"Maby some more contact afterwards. Questions about me and how I was doing."	***A need for moving on***	

Coding tree study 2

Quotes	Subthemes	Theme
THEME 1 (early phase)		
"When we manage to establish early contact, it becomes easier to work together at the end."	***Early involvement of primary care nurses***	**The importance of information and dialogue in the early phase**
"We need to help them create a palliative plan and clarify important aspects. Try to avoid situations where decisions must be made quickly and where family caregivers may not be prepared."	***Advance care planning***	
"It was a good process because we cooperated: Palliative team, general practitioner, the nursing home, and family caregivers."	***The family caregivers as a part of the team***	
THEME 2 (middle phase)		
"We have the opportunity to create a space where the patient and families can prepare for death."	***Trust***	**Creating a space for dying**
"Family caregivers sometime express: 'You must get the patient to the nursing home, but please don`t tell him/her that the words come from us.'"	***To balance conflict of interest***	
"There was a mother with small children who said she hoped to recover. The nurse then replied: 'Yes, I hope so too, but we must have an alternate plan.'"	***Emotional reciprocity***	
THEME 3 (terminal phase)		
"Family caregivers require explanations about the dying process, and how to meet the needs of a dying patient."	***Common understanding of the treatment***	**Family caregivers' acceptance of death**
"We offer bereavement counseling four to six weeks after the death."	***Routine of bereavement counseling after death***	
"This provides an opportunity to ask questions about what occurred."	***Communication about the process of dying***	

Coding tree study 3

Quotes	**Subthemes**	**Theme**
THEME 1 (early phase)		
“Getting cancer is terrifying and dying is difficult; we all want to live.”	***Emotional reciprocity***	**Beneficence for the patient and family caregivers in the early phase**
“We must understand that it is our responsibility to choose the best treatment. It creates insecurity if the patient has to choose his treatment.”	***Physicians’ treatment choices***	
“It is important that family caregivers are well informed and included in decisions about who will follow-up.”	***Creating security for patients and family caregivers***	
THEME 2 (middle phase)		
“I experience that most people prefer to have an open and good dialogue. They are grateful after the difficult conversation.”	***Patient and family caregivers’ involvement***	**Autonomy and shared decision-making in the middle phase**
“I think being assigned appointments regularly makes it easier for the patient, and they do not feel that they are taking my time. I am the one who gives time. If they do not want the consultation, they actively cancel themselves.”	***Continuity of care***	
“Family caregivers must be in place. It is so easy and so difficult at the same time.”	***Family caregivers as resources***	
THEME 3 (terminal phase)		
“The most important thing we can do to help them cope with their grief is what we do along the way. If we have done a bad job a bereaved conversation will not save the grieving process.”	***Early involvement of family caregivers***	**Family involvement in the terminal phase**
“We use to support the family caregivers and help them understand. Sometimes the symptoms bother the family caregivers more than the patient.”	***Autonomy maintained by family***	
“If there have been complicated processes and stress about treatment clarifications regarding symptom relief, the physicians might be involved in the bereaved conversation.”	***Bereavement conversations***	

Paper I, II and III

Paper I

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RESEARCH ARTICLE

Silent voices: Family caregivers' narratives of involvement in palliative care

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Abstract

Aim: To explore how family caregivers experience involvement in palliative care.

Design: A qualitative design with a narrative approach was used.

Methods: Purposive sampling and narrative interviews were conducted. Eleven bereaved family caregivers for patients with cancer receiving palliative care were interviewed in Mid-Norway between November 2016–May 2017.

Results: We identified four themes related to family caregivers' experiences of involvement in the early, middle, terminal and bereavement phases of palliative care: (a) limited involvement in the early phase; (b) emphasis on patient-centred care in the middle phase; (c) lack of preparation for the dying phase; and (d) lack of systematic follow-up after death. Family caregivers experienced low level of involvement throughout the palliative pathway.

Conclusion: The involvement of family caregivers in palliative care may not be proportional to their responsibilities. The needs of family caregivers should be addressed in nursing education to give nurses competence to support family caregivers in providing home-based care.

KEYWORDS
cancer, caregivers, decision-making, narratives, nurses, nursing, palliative care, primary health care

1 | INTRODUCTION

Palliative care is an approach that improves the quality of life of patients facing life-threatening illness and their families (World Health Organization, 2009). The European Association for Palliative Care (2008) has identified the following values for patients in hospice and palliative care in Europe (European Association for Palliative Care, 2008): autonomy, dignity, relationship between patient–healthcare professionals, quality of life, position towards life and death, communication, public education, multi-professional and interdisciplinary approach and grief and bereavement. These values are mainly focused on the needs of the patient and conditions for providing good palliative care and the situation of family caregivers are less emphasized.

The symptom burden among patients in palliative care is often substantial (Laugsand, Kaasa, Hanks, & Klepstad, 2009; Teunissen et al., 2007). Home-based palliative care is associated with improved symptom control, better quality of life for the patient and reduced use of healthcare resources (Rabow et al., 2013) and family caregivers play an essential role in facilitating home-based palliative care (Knighting et al., 2016; Reigada, Pais-Ribeiro, Novella, & Gonçalves, 2015; Woodman, Baillie, & Sivell, 2016). Internationally, there is a goal to promote home-based care and it is therefore important to gain knowledge about how family caregivers experience involvement during different phases of palliative care.

1.1 | Background

Home-based palliative care entails more responsibility for family caregivers (Knighting et al., 2015; Proot et al., 2003). Several studies have shown that family caregivers balance the care burden with what they can cope with (Andershed, 2006; Proot et al., 2003; Woodman et al., 2016). According to one study, family caregivers who were supported in their role reported a positive home-care experience, while some family caregivers felt pressure to provide home care from the patient, relatives or health professionals (Woodman et al., 2016). A study from Sweden showed that family caregivers could feel doubt, ambivalence and anxiety about providing palliative care. Family caregivers in that study did not consider the consequences of home-based palliative care for themselves as long as it was the patient's clear wish (Linderholm & Friedrichsen, 2010). Care burden, restrictions on activities, fear, insecurity, loneliness, the prospect of death and lack of emotional, practical and information-related support are factors that are considered to increase caregiver vulnerability and the risk for fatigue and burnout (Proot et al., 2003).

A meta-synthesis (Fringer, Hechinger, & Schnepp, 2018) of studies from Europe, the United States and Canada showed that palliative patients and family caregivers wanted to maintain normality in their daily life. They experienced challenges dealing with their life situation and achieving balance in everyday life. Supportive and distressing factors influenced the patient and family caregivers when trying to maintain normality and they had to deal with changed roles when anticipating the future.

The dominant ideal in Western culture is individual autonomy, which emphasizes the patient's ability to make an informed, independent choice (Brogaard, Jensen, Sokolowski, Olesen, & Neergaard, 2011; Ho, 2008). This view is also supported in the recent Lancet Oncology Commission (Kaasa et al., 2018), which highlighted patient-centred care. While several definitions of patient-centred care exist, the concept generally refers to patient involvement in care and the individualization of patient care (Epstein & Street, 2011; Kitson, Marshall, Bassett, & Zeitz, 2013; Rathert, Wyrwich, & Boren, 2013). This understanding of patient-centred care can be interpreted as contradictory to the World Health Organization's definition of palliative care (World Health Organization, 2009), which also emphasizes the needs of the family. Although some research has emphasized the family perspective in patient-centred care, most research in palliative care has adopted the individual perspective (Etkind et al., 2015; Kitson et al., 2013; Rathert et al., 2013; Robinson, Callister, Berry, & Dearing, 2008). Professional care based on humanistic values may promote patients' and relatives' sense of coherence and involvement (Andershed & Ternestedt, 2001) and research has demonstrated that family caregivers who are involved in the decision-making process cope better with home-based care (Stajduhar & Davies, 2005). Jack, Mitchell, Cope, and O'Brien (2016) emphasized the importance of comprehensive care in supporting patients and older family caregivers.

Family caregivers may be considered an integrated component of the patient's identity and an important part of the patient's life (van Nistelrooij, Visse, Spekkink, & de Lange, 2017). Family caregivers are considered the key persons in palliative home care and may provide a holistic family view (Brogaard et al., 2011).

However, family caregivers who provide home-based care may feel unprepared for the role and often neglect their own needs (Stajduhar & Davies, 2005). A study from Wales (Pottle, Hiscock, Neal, & Poolman, 2017) showed that while patients maintained a sense of normality by staying at home, family caregivers felt the opposite; their normality was lost. The patients' views and needs took precedence over those of the family caregivers. Family caregivers might experience more distress than the patient but receive less social support and some feel overwhelmed by the situation and the burden of making decisions without understanding the consequences of those decisions (Rakic et al., 2018). To be fully informed about how the disease is progressing and what could happen when the patient's disease becomes worse is seen as crucial (Knighting et al., 2015).

A study from Toronto (Mohammed et al., 2018) showed that the family caregivers felt they had to take a more active role when the patient received care at home. It was difficult to navigate in the home-care system and to cooperate with all the different professional caregivers. Most of the family caregivers had never seen death before and they therefore needed detailed explanations about the dying process.

Palliative care involves bereavement support for family caregivers (World Health Organization, 2009), and assessment tools have been developed that evaluate family caregivers' need for support (Aoun, Bird, Kristjanson, & Currow, 2010; Ewing, Brundle, Payne, & Grande, 2013; Ewing & Grande, 2013; Knighting et al., 2015; Thomsen, Guldin, Nielsen, Ollars, & Jensen, 2017). Thomsen et al. (2017) demonstrated that 75% of family caregivers who underwent a systematic risk and need assessment received their own support plan, which enabled better follow-up and more targeted support. The intervention was based on risk factors listed in the “Bereavement support standards for specialist palliative care services” (Hudson et al., 2012).

Røen et al. (2018) have explored factors promoting carer resilience. A personal relation to the healthcare providers was identified as a particularly important resilience factor. Available palliative care, information about the illness, prognosis and death were also important.

However, there is a lack of knowledge regarding family caregivers' experience of involvement in the different phases of the palliative care. Such knowledge may help to improve palliative care by identifying deficiencies in the different phases and this insight could be used to empower family caregivers and facilitate better care.

2 | THE STUDY

2.1 | Aim

The aim of the study was to explore how family caregivers experience involvement in palliative care. The research question was as follows: How do family caregivers experience information and involvement in the different phases of palliative care?

2.2 | Design

This study had a qualitative design with a narrative approach (Chase, 2005; Holloway & Freshwater, 2007; Patton, 2015). A narrative approach was chosen to highlight the perspective of family caregivers (Holloway & Freshwater, 2007), and the narrative interviews were conducted with open-ended questions (Brinkmann & Kvale, 2015).

Thompson's theoretical framework of five levels of patient-desired involvement was used in the study (Thompson, 2007). Each level represents different positions of power, ranging from non-involvement to full autonomy. Participation and involvement consist of the following five components: (a) contributing to action sequences; (b) influencing the problem definition; (c) sharing in the reasoning process; (d) influencing decision-making; and (e) experiencing emotional reciprocity. Although the theory was developed to understand patient involvement, the components have been successfully applied to family caregivers and the theory therefore provides a useful framework for understanding family caregiver involvement (Aasen, Kvangarsnes, Wold, & Heggen, 2012).

2.3 | Participants

The informants were chosen by purposive sampling of informants with maximum variation (Brinkmann & Kvale, 2015). The inclusion criteria were as follows: (a) the family caregivers had followed the patient closely in palliative care trajectory; (b) the patient had received services from both primary and specialist health care; (c) the family caregivers were able to speak the Norwegian language proficiently; (d) the family caregivers were older than 18 years; (e) the family caregivers had lost their relatives 3–12 months prior to the interview; and (f) cancer was the cause of death. We conducted eleven narrative interviews (Table 1).

TABLE 1 Characteristics of study participants

	Participants (total *N* = 11)
Interviewed in the relative's home	9
Interviewed in a community institution	2
Female	9
Male	2
Higher education	7
Lower education	3
Spouse	9
Daughter/son	2
<30 years	0
31–40 years	2
41–50 years	1
51–60 years	3
61–70 years	2
71–80 years	3

2.4 | Data collection

The informants were recruited by oncology nurses in municipalities. The locations for the interviews were chosen by the family caregivers: nine participants were interviewed in their homes and two were interviewed in a public healthcare centre. The interviews were recorded and transcribed immediately afterwards (Creswell, 2014; Polit & Beck, 2012). The interviews were conducted by the first author. In the interviews, the open-ended questions posed to the family caregivers focused on four pre-defined phases of the palliative care: the early, middle, terminal and bereavement phases (Table 2). Prior to the interviews, the informants were informed of how the various phases were defined. The family caregivers were encouraged to lead the interviews. The interviewer had a passive role, supporting the interviewees (Holloway & Freshwater, 2007; Patton, 2015). The interviews took place between November 2016–May 2017 and lasted between 50–180 min. After 11 interviews, we considered the data to be saturated, as the data tended to become repetitive and redundant (Saunders et al., 2018).

2.5 | Ethical considerations

The family caregivers could be grieving at the time of the interviews and this was taken into consideration during the interviews. The project was undertaken according to research ethics guidelines (General Assembly of the World Medical Association, 2014). Informed written consent was given by the participants at the start of the interview. The Regional Committee on Medical and Health Research Ethics determined that the study did not need approval (2016/978/REK NORD). The Data Protection Official for Research approved the study (2016/960-25).

2.6 | Data analysis

An inductive approach was adopted when analysing the interviews, with a focus on the narrative plot (Holloway & Freshwater, 2007). First, a holistic impression of the interviews was obtained (Brinkmann & Kvale, 2015). Meaningful units in the interviews

TABLE 2 Interview guide

Can you tell me how you experienced the palliative care pathway?
How did you experience the information you received in different phases of the palliative care pathway (e.g., the early phase, middle phase, terminal phase, and bereavement phases)?
How did you experience being involved in the different phases of the palliative care pathway (e.g., the early phase, middle phase, terminal phase, and bereavement phases)?
Is there anything else you want to add?

were identified for different phases in palliative care, guided by Thompson's theory of involvement (Thompson, 2007; Thompson, Ruusuvuori, Britten, & Collins, 2007). By using a narrative approach (Holloway & Freshwater, 2007), we coded palliative care into an early palliative phase, a middle palliative phase, a terminal phase and a bereavement phase. We defined the early palliative phase as the first days following the diagnosis of incurable disease, the middle palliative phase as the time between the early phase and the terminal phase, the terminal phase as the last weeks before death and the bereavement phase as the period following after the patient's death. By focusing on content, form and context in the storyline of the interviewees, a theme was identified for each phase and the story was subsequently organized with a chronological structure (Patton, 2015). The themes were built by organizing the data into increasingly more abstract units (Table 3). The inductive process involved working back and forth between the data and the themes until the researchers had a comprehensive understanding of the interviews (Creswell, 2014). The researchers worked together in the analysis process and various interpretations were useful for developing an intersubjective understanding of the narratives (Wertz et al., 2011).

2.7 | Rigour

The informants' stories are interpreted and retold by researchers and researchers can be seen as co-authors of the narratives in a study (Holloway & Freshwater, 2007). However, credibility is a fundamental goal of qualitative research (Holloway & Freshwater, 2007; Polit & Beck, 2012).

The first author had experience as an oncology nurse. Being that close to the field could represent an obstacle to an open-minded and impartial position (Patton, 2015). The interviewer and the interviewees did not know each other. To prevent bias, the co-authors were strongly involved in the analysis through the process of communicative validation (Brinkmann & Kvale, 2015). All the authors read the transcripts and participated in discussions about coding and identifying the themes. The themes derived from the data (Tong, Sainsbury, & Craig, 2007) expressed involvement in different phases of palliative care. The findings include rich descriptions to increase transferability (Polit & Beck, 2012).

3 | FINDINGS

Eleven family caregivers shared their experiences being involved in palliative care. The narratives consisted of four interrelated themes: (a) limited involvement in the early phase; (b) emphasis on patient-centred care in the middle phase; (c) lack of preparation for the dying phase; and (d) lack of systematic follow-up after death. Low involvement was a common feature in the stories.

3.1 | Limited involvement in the early phase

In the early phase, the family caregivers felt that they were thoroughly informed about the diagnosis, treatment and severity of the disease: A female spouse told it like this: "We felt well informed; The doctor told it like it was" (FC-7). The message that the patient had entered the palliative phase was generally provided by a physician at the hospital. In most of these situations, the family caregivers were present when the information was given. However, one of the informants felt that the seriousness of the diagnosis was excessively stressed. Another emphasized the importance of information to minimize uncertainty regarding palliative care for the patient and the family caregivers. "I would have liked a bit more information, not necessarily about when it would be over, but about how the process would be" (FC-10). This young husband also said that the information provided depended on the question he asked.

However, despite being satisfied with the thoroughness of the information provided, several family caregivers expressed a desire to speak with health personnel about the expected disease trajectory and how this would affect their role as caregivers and the family situation. They expressed that they wanted more information about how the disease would develop and what to expect in

TABLE 3 Illustration of analytic steps followed to identify relevant themes

Coding	Quotations	Subtheme	Theme
Early palliative phase	"We felt well informed; The doctor told it like it was"	Information-giving	Limited involvement in the early phase
	"We respected her desire not to be too informed about prognosis, but I would have liked to know a bit more"	Family caregivers' independent need for information	
	"He decided. He let us know early on that he wanted to stay at home"	The patient decided	

the different phases of the illness. Importantly, the caregivers' and patients' desires for information were not always congruent. One son of a mother expressed this: “We respected her desire not to be too informed about the prognosis, but I would have liked to know a bit more” (FC-5). One family caregiver wished to speak with the physician without the patient present. However, the family caregiver found it difficult to make this request in the presence of the patient. Another family caregiver was invited to speak with the physician but found it difficult to accept the offer in front of the patient. A young husband expressed: “That would mean you want to talk about something that you can't address with the patient present” (FC-10). These difficulties hindered the family caregivers from having a dialogue with healthcare providers and from obtaining the information they needed to be prepared for the different phases of the palliative care.

Although the patient wished to die at home, several family caregivers expressed ambivalence in this regard. A female spouse said: “He decided. He let us know early on that he wanted to stay at home” (FC-3). These family caregivers felt that they were not part of that decision and some felt it was difficult to fulfil the patient's wish. The family caregivers expressed that they were offered few opportunities to define their own needs and challenges. “I was there to care for him and look after him—my own needs were neglected” (FC-3).

Some of the family caregivers had expressed to healthcare providers at an early stage that they did not want the patient to die at home because they did not feel able to bear the burden. “They wanted us to care for our mother at home, but we could not take that responsibility” (FC-8). In cases such as this, the patients spent the terminal phase in a nursing home.

3.2 | Emphasis on patient-centred care in the middle phase

In the middle phase of palliative care, the family caregivers noted that the patients' wishes and needs were taken seriously by the healthcare providers both in the hospital and in primary care. However, they expressed that their own needs as family caregivers were occasionally neglected. A female spouse said that although she felt she was listened to, only her husband's illness and needs were discussed. She had told the healthcare provider that caring for her husband was too burdensome for her. “I told the nurses, but it was my husband who decided” (FC-4). Another female spouse described this issue as follows: “Obviously, we were given the opportunity to discuss our problems, but it depended on what he would accept” (FC-6). In some cases, the patient's unwillingness to accept help prevented family caregivers from enlisting necessary aid from healthcare services. “It was extremely tiring, because he didn't want me to bring in a lot of people and make such a fuss; I was supposed to take care of everything and be in control all the time” (FC-3). The role of caregiver overshadowed the role of family member and prevented caregivers from being close to the patient and providing emotional support. A wife expressed the following: “When he was ill with vomit and diarrhoea, I cared for him, but in a way I couldn't be close to him, near him; I was an assistant. I wished I had more time with him” (FC-6). The family caregivers often felt they had too much responsibility.

Several said that they did not use the offered services enough, or that they used them too late because they were unable to foresee what kind of services they would need. A female spouse said: “I should have asked for help much earlier. When I got help, I hadn't slept for three months” (FC-3). She acknowledged that her husband's unwillingness to receive health services in their home was a reason for the delay.

While the patient was in a primary healthcare setting, the family caregivers were uncertain about who was responsible for medical treatment. A female spouse expressed this: “I thought it was the physician on the palliative team or in the cancer unit who was in charge and not the family doctor” (FC-11). It was confusing to not understand who was in charge or who the caregivers should contact when a need arose. The informants wanted the family doctor to have a central part in palliative care and some said that the family doctor had provided good support and information. A son expressed it like this: “The family doctor communicated well with other health personnel who were involved in the treatment. Thus, we got important information that mother had short time to live” (FC-5).

A wife expressed that the nurse wanted the family doctor to pay the patient a visit at home to assess the situation because the patient's condition was deteriorating. However, the patient did not want the doctor to visit: “I suspected that he was afraid the family doctor would send him to the nursing home” (FC-6). This family caregiver wanted the family doctor to be involved in palliative care. The family caregivers expressed that there were conflicts of interest between patients and family members regarding various decisions in palliative care.

3.3 | Lack of preparation for the dying phase

The family caregivers experienced a lack of involvement in planning for the terminal phase. While they felt a heavy responsibility, none talked about being involved in making plans for the terminal phase. The family caregivers experienced this phase as difficult, as they had no knowledge about what lay ahead. A son put it like this: “I wondered whether she would be in a coma for days” (FC-5). A female spouse of a patient who had experienced a difficult course of illness said that if she had known how challenging providing care in the terminal phase would be, she would not have taken on the burden. The need for more information about the process of dying was therefore emphasized by several family caregivers.

The family caregivers said that they wished they had contacted health personnel at an earlier stage in palliative care, as it would have enabled them to obtain necessary help and information when they needed it. “There was no contact until I contacted them” (FC-3). The informants described how important it was to have someone from healthcare services to call if needed. Among the family caregivers, establishing a dialogue with healthcare providers and being listened to were considered important steps to improving their involvement in the terminal phase. However, some experienced situations where the patient was unwilling to provide information about his/her condition to family caregivers, preventing cooperation between health personnel and family caregivers.

When the patients were at home, the caregivers often experienced being alone with the responsibility for the patient's care. The burden of providing care in the final stages of life was not recognized by healthcare professionals, and the family caregivers sometimes felt they were left to handle the tasks on their own. Taking responsibility for her husband both night and day was perceived as frightening and challenging. Conversely, when visiting the patient in a nursing home, they felt well cared for by the health professionals. A female spouse told about the experience of visiting the patient. “It was good to be at the nursing home. The girls and I, we were all there and we were treated in a nice way” (FC2).

3.4 | Lack of systematic follow-up after death

The family caregivers shared different stories about their experience with follow-up after the death of the patient. Some met with the local community oncology nurse and some met with healthcare providers from the hospital. The informants believed there should be an offer of follow-up, even though some declined such an offer. One female spouse stated the need for a systematic follow-up offer after death: “I think it should have been a systematic process regarding this” (FC-6). The family caregivers expressed that it was especially important to talk with the nurse who had been present on the last day of the patient's life, as they had many questions about the process of dying. “There are many questions I would like to ask about what happened in the last hours he lived” (FC-1). Such answers were considered important in the process of grieving and moving on with their lives.

The family caregivers experienced a lack of support in the bereavement process. Most of the informants expressed that there had been no offer of follow-up. A female spouse said it like this: “Maybe some more contact afterwards. Questions about me and how I was doing” (FC-1). This family caregiver expressed that she had received support from the local priest and her own family doctor. Among the caregivers, being contacted by health professionals after the patient died was seen as important to be able to process their sorrow and move on with life. Based on the stories told, there seemed to be a lack of systematic follow-up from healthcare providers. The family caregivers expressed that a conversation after the patient's death might have been valuable in helping to get over the sorrow and loss.

4 | DISCUSSION

The aim of this study was to obtain insight into how family caregivers experience involvement in palliative care. The family caregivers expressed that although they were well informed about the patients' diagnoses, they experienced low levels of involvement in defining problems and challenges regarding the care of the patient. While the informants felt that the patient received patient-centred care, they felt that their own needs were neglected. They also felt unprepared for the process of dying. The family caregivers experienced a lack of systematic follow-up after the patient died. Dialogue and being listened to by the healthcare providers were highlighted as important.

While the family caregivers were well informed about the patients' diagnoses, they also wanted to be more involved in the decision-making process regarding palliative care. It appeared that the need for information was mostly defined by the patient and healthcare providers and that their communication was characterized by paternalism (Thompson et al., 2007). Thompson et al.'s (2007) components of participation were not readily identified in the informants' descriptions of involvement, and this was exacerbated when the symptom burden was high and when the patient did not want to receive appropriate health services. The framework for involvement and participation described by Thompson et al. (2007) was useful in highlighting shortcomings in the involvement of family caregivers. This holistic framework consists of three elements: components, levels and context, which were valuable in identifying family caregivers' involvement in different phases of palliative care.

In the present study, the family caregivers wanted more information about practical issues related to the daily care of the patient. Funk et al. (2010) suggested that being involved in care and feeling able to effectively provide palliative care can strengthen family caregivers. The lack of preparation, knowledge and ability of family caregivers is well known. Earlier research has shown that the feeling of being unprepared, especially regarding knowledge of symptoms and decisions about medication management, can represent a considerable burden for many family caregivers (Funk et al., 2010; Rakic et al., 2018). The family caregivers in our study shared stories indicating that the dying person and his/her caregivers have different needs, and this is well known in the literature (Male, Fergus, & Stephen, 2015; Pottle et al., 2017). The need for information and the provision of practical support are two areas where patients' and family caregivers' opinions can differ. The rhetoric around patient-centred care (Etkind et al., 2015; Kitson et al., 2013; Robinson et al., 2008) may prevent awareness of family caregivers' unmet needs in palliative care. Hence, a family perspective should be included in the concept of patient-centred care.

In our study, the caregivers talked about how difficult it was to be in the role of an “assistant” instead of the role of a close family member. Studies have reported that changing roles can be difficult for family caregivers involved in palliative care (Fringer et al., 2018). To handle multiple roles could lead to over-exertion and these contradictory roles must be balanced (Fringer et al., 2018). In our study, this need for balance was significant, especially when the patient rejected support offered by healthcare providers. Research has showed the importance of a personal relationship between family caregivers and health personal and detailed information about the dying process to handle the challenges (Mohammed at al., 2018; Røen et al., 2018).

We found that healthcare providers are not always sufficiently aware of family caregivers' needs for information and practical support, especially in the terminal phase. From an ethical perspective, it has been suggested that family caregivers should be conceptualized as an integral component of the patient's identity and should therefore be included in the decision-making process from the beginning rather than being seen as a third party to the doctor–patient relationship (van Nistelrooij et al., 2017). Given the crucial role of family caregivers in providing home-based care, maintaining a high degree of involvement and support for family caregivers in palliative care is warranted.

Our informants experienced the terminal phase as being particularly difficult. A lack of knowledge about the last phase left them poorly prepared for what lay ahead. Previous research has shown that health professionals underestimate family caregivers' need for information about palliative care, death and dying (Collins, McLachlan, & Philip, 2018). Family caregivers need healthcare providers to explain in a clear language what is going to happen during the process of dying, without assuming any prior understanding (Dose et al., 2015).

The family caregivers also experienced a lack of follow-up after the patient had died. Both the specialist health service and the municipal health service had routines in relation to following up with bereaved individuals. Continued follow-up of family caregivers is part of the guidelines from the WHO for palliative care (Integrating Palliative Care & Symptom Relief into Primary Health Care, 2018), but it appears that these guidelines may not be manifested in a systematic way. Implementing assessment tools to evaluate needs for support might raise awareness among healthcare providers about the needs of family caregivers, including caregivers' obvious needs and needs they are unaware of (Ewing & Grande, 2013).

The findings from this study show deficiencies in the involvement of family caregivers in various phases of palliative care. Family caregivers' narratives can be used to improve various assessment tools that might strengthen their involvement in palliative care.

4.1 | Limitations

The informants might be grieving when they were interviewed, and this could have influenced the way they communicated their experiences. The interviews were conducted 3–12 month after the family member's death. This might have affected how family caregivers remembered what had happened. The findings represent the family caregivers' subjective experiences as interpreted by the researchers. The findings from our study cannot be generalized, but it is reasonable to assume that the findings can be applied to similar situations and contexts as well as being family caregivers to patients with other diagnoses.

5 | CONCLUSION

Health authorities recommend that patients receiving palliative care should have the opportunity to spend more time at home at the end of their lives. This entails increased responsibility for family caregivers. This study demonstrated that family caregivers experience limited of involvement in planning palliative care. Their voices seem to be silent and the involvement of family caregivers is not in proportion to their responsibilities. Consequently, the needs of family caregivers in the palliative care trajectory must be addressed to successfully provide home-based care. Family caregivers' involvement in palliative care should be a topic in nursing education and continuing education for nurses.

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CONFLICT OF INTEREST

The authors did not declare any conflict of interests.

AUTHOR CONTRIBUTIONS

AST, MK, BJL and TH: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data. AST, MK, BJL, TH, MT and TSM: Involved in drafting the manuscript or revising it critically for important intellectual content. AST, MK, BJL, TH, MT and TSM: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. AST, MK, BJL, TH, MT and TSM: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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ORIGINAL ARTICLE

Nurses' experiences of compassionate care in the palliative pathway

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Abstract

Aims and objectives: The aim was to explore how nurses experience compassionate care for patients with cancer and family caregivers in different phases of the palliative pathway.

Background: Compassion is fundamental to palliative care and viewed as a cornerstone of high-quality care provision. Healthcare authorities emphasize that patients should have the opportunity to stay at home for as long as possible. There are, however, care deficiencies in the palliative pathway.

Design: This study employed a qualitative design using focus groups and a hermeneutic approach.

Methods: Four focus groups with three to seven female nurses in each group were conducted in Mid-Norway in 2018. Nurses' ages ranged from 28–60 years (mean age = 45 years), and they were recruited through purposive sampling ($N = 21$). Compassionate care was chosen as the theoretical framework. Reporting followed the COREQ guidelines.

Results: Three themes expressing compassionate care related to different phases of the pathway were identified: (a) information and dialogue, (b) creating a space for dying and (c) family caregivers' acceptance of death.

Conclusions: This study showed that it was crucial to create a *space for dying*, characterized by trust, collaboration, good relationships, empathy, attention, silence, caution, slowness, symptom relief and the absence of noise and conflict.

Relevance to clinical practice: The quality of compassion possessed by individual practitioners, as well as the overall design of the healthcare system, must be considered when creating compassionate care for patients and their family caregivers. Nursing educators and health authorities should pay attention to the development of compassion in education and practice. Further research should highlight patients' and family caregivers' experiences of compassionate care and determine how healthcare systems can support compassionate care.

KEYWORDS
cancer, compassion, nurses, palliative pathway, primary care

1 | INTRODUCTION

Compassion is fundamental to palliative care and can create an environment of safety for patients and family caregivers. Compassionate care is built on trust and good relationships between the patient, the family and healthcare personnel (Brito-Pons & Librada-Flores, 2018; Larkin, 2016).

There are various definitions of compassionate care (Crawford et al., 2014; Feo et al., 2018; Strauss et al., 2016). In this study, we followed a broad description of compassion as involving an awareness of, or a sensitivity to, the pain or suffering of others that results in taking verbal, nonverbal or physical action to remove, reduce or alleviate the impact of such affliction (Gilbert, 2013). This description is relevant because research has shown that patients and their family caregivers experience deficiencies in palliative care provision (McEwen et al., 2018; Røen et al., 2018; Tarberg et al., 2019). A Norwegian study found that family caregivers experienced limited involvement, a lack of preparation for the dying phase, and unsystematic follow-up after death (Tarberg et al., 2019). An Australian study showed a gap between guidelines and family caregivers' experiences of emotional and psychological support in palliative care (Aoun et al., 2017).

The integration of palliative care with oncology is recommended; however, this has been insufficiently addressed in healthcare systems (Kaasa et al., 2018). Six main elements of patient-centred care are highlighted: (1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort-relief of bothersome symptoms; (5) emotional support-relief of fear and anxiety; and (6) involvement of family and friends (Kaasa et al., 2018). Nurses can play a key role in integrating palliative care and oncology by providing compassionate care (Brito-Pons & Librada-Flores, 2018).

In this study, we explore nurses' experiences of compassionate care for patients and family caregivers in the palliative pathway. Nurses work closely with patients and family caregivers and are therefore a relevant population in which to explore compassion.

2 | BACKGROUND

One recent study, which included participants from 15 countries, explored nurses' understanding of compassion (Papadopoulos et al., 2017). Nurses reported that sociopolitical structures constrained and influenced their provision of care. Lack of time was also identified as an obstacle for the provision of compassionate care. Five components were identified as comprising compassion: (1) investing time in the nurse–patient relationship, (2) presence, (3) going the extra mile, (4) personalization and (5) advocacy (Papadopoulos et al., 2017).

What does this paper contribute to the wider global clinical community?

- It provides insight into nurses' role in compassionate care in different phases of the palliative pathway.
- It highlights the importance of early engagement with family caregiver as a key element of compassionate care.
- Nurses play a crucial role in creating *a space for dying* which is important for patients' and their family members' preparation for death.

Compassion requires action (Larkin, 2016). True compassion is expressed through the highest level of clinical practice, which addresses the totality of symptom burden and complex needs. Compassion implies a sense of coherence, nurses being able to communicate a compassionate essence, based on knowledge, proactivity and interconnectedness in the delivery of nursing. Compassion is not just about individual responses, but rather about how nurses are enabled by the system to sustain and support themselves in the complexity of palliative care (Larkin, 2016).

To support the patient in the process of dying, previous researchers have identified some key elements deemed important by community nurses: symptom control, patient choice, honesty, spirituality, interprofessional relationships, organization and the provision of seamless care (Griggs, 2010). Building trust and knowledge with patients and their families is valuable during end-of-life care. Building trust depends on nurses' availability (Stajduhar et al., 2011). Compassionate care facilitation includes the personal and relational characteristics of the primary care nurse, the organizational framework and an individually tailored care system. Barriers to compassion include personal challenges, relational challenges, system challenges and maladaptive responses (Singh et al., 2018).

Nurses have a coordinating role between patients, families and other health professionals, which is also challenging (Sekse et al., 2018). Wilson et al. (2014) reported that primary care nurses have noted that family dynamics impact on complex and difficult situations. The family, patient and nurses may all be at different stages in the acceptance of death. Further, conflict may arise when patients conceal information about their medication or misunderstand and feel suspicious around its use (Lund et al., 2015; Wilson et al., 2014).

Many of the definitions of compassionate care are general and do not consider that compassionate care will have different expressions in different contexts for different patients and situations. A discursive paper from New Zealand presented a bi-cultural approach to providing compassionate care during end-of-life care (Robinson et al., 2019). The Kapakapa Manawa Framework was developed by drawing on empirical research that captured the experiences of palliative care in hospitals from the perspectives of bereaved families (Dewar & Nolan, 2013; Durie, 1985; Gott et al., 2019). The researchers extended the framework to encompass Māori values of compassion during end-of-life care. This model differs from others by noting how compassion should be integrated into nursing practice by referring explicitly to compassion as a verb. The model considers patients' cultural background in care provision and the family members involved, which may be used to support the implementation of the relational component of 'Fundamentals of Care' (Robinson et al., 2019). Knowing enough about patients and developing trust is an important element in this framework. Conceptualizing compassion as an action may be used as a platform on which to develop meaningful relationships (Robinson et al., 2019).

This framework outlines four values, which optimize compassionate nursing in the palliative pathway: (1) relationships that express care, (2) the process of establishing good relationships, (3) the use of contextualized knowledge and (4) a reciprocal process of mutual respect between people. This model refers to a Māori concept that relates to the process of establishing relationships and nurturing ongoing connections through effective inter-relational caring. This understanding of compassion brings the nurse and the patient closer together and provides a better understanding of the patient as a person (Robinson et al., 2019).

In our study, we explored compassionate care in the Norwegian context. In Norway, 13 per cent of the population died at home in 2018 (The Norwegian Institute of Public Health, 2019). The health authorities have recommended that, as more patients choose to stay longer at home, they should have the opportunity to die at home (Norwegian Ministry of Health & Care Service, 2020). Targeted measures have been designed to give everyone a dignified end of life in line with their needs and wishes. Expertise on palliation, resources and cooperation is necessary to enable nurses to fulfil these aims (Kaasa et al., 2018).

In this study, we understand compassionate care as consisting of three dimensions: noticing, feeling and responding. In addition, we consider compassionate care as an overall design of healthcare organizations (Blomberg et al., 2016; Crawford et al., 2014; Gilbert, 2013; Kanov et al., 2004; Larkin, 2016). We have divided the palliative pathway in three different parts: the first phase is defined as the first days following the diagnosis of an incurable disease, the second phase is the middle part of the incurable disease, and the third phase, also termed as the terminal phase, constitutes the last weeks and days before death (Tarberg et al., 2019). The aim was to explore how nurses experience compassionate care for patients with cancer and family caregivers in different phases of the palliative pathway.

3 | METHODS

3.1 | Design

The study employed a qualitative design with a hermeneutic approach (Gadamer, 1989; Patton, 2015). Focus groups were chosen to explore nurses' experiences through discussions with other participants with whom they had something in common – in order to promote self-disclosure (Brinkmann & Kvale, 2015; Krueger & Casey, 2015; Malpas & Gannder, 2017). The Consolidated Criteria for Reporting Qualitative Checklist were followed, see File S1 (Tong et al., 2007).

3.2 | Sampling

Informants were chosen by means of purposive sampling (*N* = 21) (Brinkmann & Kvale, 2015; Krueger & Casey, 2015). Four focus groups with three to seven female nurses in each group participated in the study. Nurses' ages ranged from 28-60 years (mean age = 45 years). Nurses from primary care facilities and from nursing homes were recruited because they had experiences in different phases of palliative care. Nurses from urban and rural areas were also included to increase data variation. Participants worked in different municipalities in Mid-Norway with 2000 to 43,000 inhabitants. Inclusion criteria were nurses who had worked in palliative care for more than three years and who could speak fluent Norwegian. Administrative nurses were excluded. Participants' demographic characteristics are shown in Table 1.

3.3 | Data collection

Nurses were recruited face-to-face by contact persons in the municipalities. A question route with open-ended questions was developed based on the study aim and earlier research (Crawford et al., 2014; Krueger & Casey, 2015; Tarberg et al., 2019). The questions were related to how nurses had experienced compassionate care in

TABLE 1 Characteristics of study participants

	Participants (total *n* = 21)
Experience in home care	7
Experience in a community institution	9
Experience in home care and community institution	5
Female	21
Male	0
Registered nurse	21
Palliative nurse	2
Oncology nurse	6
<30 years	1
31–40 years	8
41–50 years	3
51–60 years	9
Nurses from urban areas	10
Nurses from rural areas	11

different phases of the palliative pathway: namely the first, the second and the third phase. The question route was as follows:

1. Can you tell me how you experience palliative care?
2. What is important when communicating with patients and family caregivers in different phases of the palliative pathway?
3. How do you wish to collaborate with family caregivers throughout the pathway?
4. What is important about the nature of the care offered in different phases of the palliative pathway?
5. What challenges and ethical dilemmas did you experience?
6. Is there something else you want to add?

The first author was a moderator and the second author was an assistant – taking field notes and summarizing what nurses said at the end of the interviews. The focus groups, conducted in Norwegian, lasted between 60 and 90 min. They were audio-recorded and transcribed verbatim shortly thereafter by the first author (Krueger & Casey, 2015; Polit & Beck, 2012).

The interviews provided rich descriptions of nurses' perception of compassionate care in different phases of the palliative pathway. Data were collected in 2018, until no substantially new information was obtained from the last group. We considered that the data were saturated regarding all the preliminary themes. Saturation was discussed between the researchers after the interviews. Data collection and analysis went hand-in-hand (Patton, 2015). The moderator let the discussion flow naturally between participants, that is they were given the opportunity to speak openly and to participate in the focused discussion. (Krueger & Casey, 2015).

3.4 | Data analyses

We used compassionate care as a theoretical framework when interviewing the nurses. All the authors read the interviews to gain a holistic impression of the data (Brinkmann & Kvale, 2015). The first author coded the interviews related to compassionate care in the first, second and third palliative phase. The first author has worked as an oncology nurse in primary care for 10 years. Leaning on a hermeneutic approach, we were aware that her preunderstanding influenced data interpretation (Gadamer, 1989); therefore, all authors engaged in discussing the analyses and a new understanding was developed from group discussions (Brinkmann & Kvale, 2015). We used the hermeneutic circle, in which the meaning of the parts is determined by the global meaning. Consequently, we gained a new and deeper understanding of compassionate care in different phases of the pathway – both for patients and for their family caregivers (Gadamer, 1989). In the process of interpretation, it was important to read the interviews with empathy, that is we tried to understand the intentions behind what was said. This enriched our previous interpretations. In all our interpretations, our perceptions of the nurses' view of compassionate care were central (Alvesson & Sköldberg, 2018). Quotations, subthemes and themes are presented in Table 2.

3.5 | Ethical considerations

The project was undertaken according to research ethics guidelines (World Medical Association, 2013). The Regional Committee on Medical and Health Research Ethics determined that the study did not require ethical approval (no. 2016/978/REK NORD). The Data Protection Official for Research approved this study (no. 2016/960-25). All nurses were given oral and written information that they could withdraw whenever they wanted. Informed written consent was obtained by all nurses at the start of the interviews. All data were anonymized. The informants were colleagues, and we were conscious of presenting the interviews in a respectful manner (Brinkmann & Kvale, 2015).

3.6 | Rigour

Decisions were carefully described to enhance the transparency of this study (Polit & Beck, 2012) and to enable readers to evaluate the research process. Two researchers conducted the interviews, and both were experienced in performing qualitative interviews. The theoretical framework was carefully described to increase data interpretation validity (Patton, 2015). A coding tree and various stages in the analysis were described to enhance reliability in the analysis. All authors participated in discussions about data interpretation (Tong et al., 2007). Participants' quotations were presented to illustrate the themes (Table 2).

4 | RESULTS

Twenty-one nurses working in palliative care shared their experiences of compassionate care for patients and family caregivers in the palliative pathway. Three themes were identified: (a) information and dialogue in the first phase, (b) creating a space for dying and (c) family caregivers' acceptance of death. The first and the second theme relate to compassionate care for patients and family caregivers in the first and second phase of the palliative pathway, respectively. The third theme relates to family caregivers' acceptance of death in the second and third phase.

4.1 | Information and dialogue

Nurses emphasized the importance of early contact in order to provide information about what services they could offer. They often had little contact with patients and family caregivers in the first phase of the pathway. Nurses conveyed that patients and family caregivers felt shock and sadness in this first phase, and often they were not ready to meet oncology nurses from primary care. The nurses thought that this might contribute to a delayed provision of health services. An explanation provided by them was that patients and family caregivers might not have sufficient knowledge or experience to understand the importance of early involvement with health personnel: '*When we manage to establish early contact, it becomes easier to work together at the end*'. Hence, the nurses highlighted the importance of dialogue between patients, family caregivers and healthcare personnel through the course of the disease, and noted that early involvement increased their ability to provide compassionate care. Interdisciplinary collaboration between specialist healthcare services and primary healthcare was considered important to improve compassionate care.

The nurses emphasized that physicians and nurses in the hospitals had a key role in communicating the importance of early involvement in primary health services. They considered it vital to plan the palliative pathway together with the patients and family caregivers before the patient had reached the third and terminal phase. The need for advance care planning was described: '*We need to help them create a palliative plan and to clarify important aspects, try to avoid situations where decisions must be made quickly, and where patients and family caregivers may not be prepared*'. The nurses indicated that a palliative plan should provide patient-centred care and carry out the patient's wishes. They experienced that advance care planning led to useful information being conveyed to patients and family caregivers, created a sense of security and prepared patients and family caregivers for what was to come.

Nurses discussed the value of including family caregivers as part of the team. '*It was a good process because we cooperated: palliative team, general practitioner, the nursing home and family caregivers*'. Close collaboration between family caregivers, primary care providers and healthcare specialists made it possible to fulfil patients' wishes to die at home. Collaboration was seen as an important element of compassionate care.

4.2 | Creating a space for dying

The second phase needed to be a quiet period in which patients and family caregivers were provided with security, predictability

TABLE 2 Development of quotes into themes

Quotes	Subthemes	Theme
Theme (a)		
'When we manage to establish early contact, it becomes easier to work together at the end.'	*Early involvement of primary care nurses*	
'We need to help them create a palliative plan and clarify important aspects, try to avoid situations where decisions must be made quickly, and where patients and family caregivers may not be prepared.'	*Advance care planning*	Information and dialogue
'It was a good process because we cooperated: palliative team, general practitioner, the nursing home and family caregivers.'	*The family caregivers as a part of the team*	
Theme (b)		
'We have the opportunity to create a space, where patients and families can prepare for death.'	*Trust*	
'Family caregivers sometime express: 'You must get the patient to the nursing home, but please don`t tell him/her that the words come from us.''	*To balance conflict of interest*	Creating a space for dying
'There was a mother with small children who said she hoped to recover. The nurse then replied: 'Yes, I hope so too, but we must have an alternate plan.''	*Emotional reciprocity*	
Theme (c)		
'Family caregivers require explanations about the dying process, and how to meet the needs of a dying patient.'	*Common understanding of the treatment*	
'We offer bereavement counseling four to six weeks after the death.'	*Routine of bereavement counselling after death*	Family caregivers' acceptance of death
'This provides an opportunity to ask questions about what occurred.'	*Communication about the process of dying*	

and clarification. Nurses were engaged and emotionally affected when they talked about this topic. They emphasized the importance of creating a space for dying, and that there were better facilities than hospitals in which to create this space: '*We have the opportunity to create a space, where patients and families can prepare for death*'. According to the nurses, a space for dying was characterized by trust, collaboration, good relationships, empathy, attention, silence, caution, slowness, symptom relief and the absence of noise and conflict. Nurses perceived that patients and families had best experienced compassionate care in primary healthcare at home and in nursing homes.

Challenges in the interactions with patients and family caregivers were a topic in the focus groups. Balancing a conflict of interest between family members could be challenging and could prevent adequate planning for the impending death. This could hinder the process of 'creating a space for dying'. Nurses expressed that patients and family caregivers, as well could have different needs: *'Family caregivers sometimes express, "You must get the patient to the nursing home; but please don't tell him/her that the words come from us."'* In such a situation, just whose interests should be prioritized, becomes an ethical dilemma for health personnel. Nurses had to be aware of patients' and family caregivers' mental and physical needs. The importance of trust and good interpersonal relationships in providing compassionate care was crucial.

Communication skills were also an essential competence with regard to providing compassionate care. Nurses described how they tried to prepare patients and families for the last days and death. They indicated that certain patients could not relate to their impending death: *'There was a mother with small children who said she hoped to recover. The nurse then replied, "yes, I hope so too; but we must have an alternate plan."'* This way of responding to the patient illustrates that the nurse is listening to the patient in a way that conveys both hope and realism. Communicating in an empathic way is an important part of compassionate care.

Another recurrent topic was the importance of nurses having expertise in symptom relief. Nurses experienced that there was a lack of collaboration between physicians and nurses. This could result in patients not receiving adequate medication in time. The nurses argued for the importance of interprofessional collaboration with regard to the provision of symptom-relieving medication in the third phase. This allowed for combined planning and the anticipation of possible difficulties, at a system level. It also required that professionals find new ways of collaborating with each other.

4.3 | Family caregivers' acceptance of death

The nurses experienced the last phase as difficult. Dilemmas arose when healthcare professionals and family caregivers had a different understanding of treatment choices; for instance, if family caregivers wanted health personnel to provide treatment and the patient did not want it. The need for information to family caregivers about palliative treatment was highlighted, especially relating to fluid and nutrition: '*Family caregivers require explanations about the death process, and how to meet the needs of a dying patient*'. Nurses had experienced that family caregivers could become despairing and angry when the patient could not eat and drink in the third phase. They had often experienced that treatment limits had not been made clear in advance. Hence, a common understanding between healthcare personnel and family caregivers was important.

After a patient's death, nurses had bereavement routines to follow, in which contact was offered to grieving family members: '*We offer bereavement counseling, four to six weeks after the death*'. Nurses in the focus groups vehemently discussed communication with the bereaved. The routines seemed, however, to differ both between municipalities and within municipalities. In some municipalities, nurses offered calls only to the bereaved family of patients who had died of cancer.

Nurses experienced that the bereaved had different needs, and some nurses expressed that it was especially important for the bereaved to meet the health professionals who had been present when the patient died. A nurse expressed it like this, *'This provides an opportunity to ask questions about what occurred'*. Some of the bereaved needed several conversations to get over the loss of their beloved ones. Nurses thought that almost everyone would benefit from a conversation with healthcare personnel after a patient had died. To help the bereaved to get over their loss was an important part of compassionate care.

5 | DISCUSSION

The focus groups provided rich data and gave a new understanding of the meaning of compassionate care in different phases in the palliative pathway. The analyses have revealed that compassionate care is contextual. Information and dialogue with patients and family caregivers was crucial in the first phase. In the second phase, the nurses highlighted the importance of creating a space for dying. In the third phase, family caregivers' acceptance of patients' death was important.

Information and dialogue with patients and family caregivers early in the pathway was an important finding in this study. Earlier research has indicated that building trust, knowledge and good relationships are important in end-of-life care (Robinson et al., 2019; Stajduhar et al., 2011). This is in accordance with the results presented in this study. The nurses advised that family caregivers should be seen as part of the team around the patient.

Our study show the significance of advance care planning, which involves patients and family caregivers in the process. The goal of advance care planning is to ensure that medical care is consistent with patients' and family caregivers' values, goals and preferences (Kaasa et al., 2018). Nurses experienced that advance care planning gave patients and family caregivers a sense of security and prepared them for future challenges. In this, they mirror the findings of Pfaff and Markaki (2017), who, in an integrative review, highlighted the significance of collaborative and patient- and family-centred care.

Nurses expressed that creating a space for dying was crucial for patients and family caregivers. The significance of creating this space has not been highlighted in previous research about compassionate care in the palliative pathway. Based on the findings in this study, it is urged that the provision of primary health care for the dying, whether at home or a nursing home, is provided with facilities, and a philosophy, which facilitates a compassionate culture for both patient and family caregiver. Larkin (2016) has argued that compassion is not just about individual responses, but rather about how practitioners are able to sustain and support themselves in the complex field of palliative care.

The importance of creating a space for dying demands that nursing managers and policymakers prioritize resources for healthcare personnel to assist them in shaping a compassionate culture (Crawford et al., 2014; Martinsen & Kjerland, 2006). Our findings support the understanding that the organization and design of services are important in compassionate care.

Family conflicts, different stages of accepting death within the family and denying families a role in decision-making are obstacles to creating compassionate care (Lund et al., 2015; Wilson et al., 2014). In this study, nurses experienced that they played a significant role by being active in creating a space for dying. We consider this space as important for patients and families in accepting and preparing for death.

Further, a lack of interdisciplinary collaboration, specifically, physicians' failure to prescribe sufficient pain relief medication were problematic. This may be an obstacle to patients receiving symptom relief in the third and terminal phase. Griggs (2010) describes symptom control as a key element in supporting patients' process of dying. International recommendations (Kaasa et al., 2018) have also highlighted the importance of physical comfort-relief of bothersome symptoms. Nurses experienced that they play a crucial role in collaboration with physicians to ensure that a patient receives effective pain relief. The supply of care and medication needs to be well-organized, so that dying patients get symptom relief also in weekends and holidays.

5.1 | Strengths and Limitations

This study illustrated compassionate care in the palliative pathway from the perspective of nurses and not from the experiences of patients and family caregivers. The study provided rich data, which we believe offers new insight into compassionate care in various phases of the palliative pathway. In the future, it is suggested that compassionate care in the palliative pathway be studied from the perspectives of patients, family caregivers and physicians, to enable us to develop a more holistic understanding.

Compassionate care was chosen as the theoretical framework (Blomberg et al., 2016; Brito-Pons & Librada-Flores, 2018; Crawford et al., 2014; Robinson et al., 2019). This framework had an impact on how the data were collected and interpreted. A hermeneutic approach assumes that the findings are an interpretation based on a theoretical framework and should be interpreted in a cultural and historical context (Patton, 2015). This background is important in interpreting compassionate care expressed by nurses in the Norwegian context. In Norwegian, there are no expressions that are synonymous with 'compassionate care'. It was therefore important to have a theoretical framework when studying this phenomenon in the Norwegian context. There is thus a need to develop concepts in Norwegian which communicate the content of compassionate care in the community of practice in Norway.

Although this study was conducted in Norway, the findings may be generalized to other countries with similar health services (Polit & Beck, 2012). The theoretical framework (Blomberg et al., 2016; Crawford et al., 2014; Gilbert, 2013; Kanov et al., 2004; Larkin, 2016) was important in revealing key elements of compassionate care at various stages of the pathway. In the interviews, we used Norwegian terms that corresponded with terms and concepts in the English theoretical framework of compassionate care. The study provides new insights of international relevance because the findings reveal existential and general challenges related to caring in the palliative pathway.

The first author has been working as an oncology nurse in primary health care for many years, and she has experience in the concepts discussed in this study. However, all the authors collaborated in the data interpretation to develop a new understanding and to ensure a holistic perspective (Gadamer, 1989; Patton, 2015).

6 | CONCLUSION

Compassionate care is different in the three phases of the pathway, and the nurses should take an active role in creating compassionate care throughout the pathway. It is crucial to create a space for dying. Trust, collaboration, good relationships, empathy, attention, silence, caution, slowness, symptom relief and absence of noise and conflicts characterize compassionate care when crating a space for dying. It is likely that the findings can provide insight into caring in the palliative pathway for patient groups with other chronic diseases.

7 | RELEVANCE TO CLINICAL PRACTICE

Nurses should involve family caregivers as a part of the team around the patient in the first phase of the palliative pathway. It is important that nurses spend time building trust. Nurses should take a coordinating role in creating a space for dying. Managers and policymakers should prioritize resources for healthcare services in shaping compassionate culture. Healthcare personnel should offer bereavement counselling in a systematic way. Compassionate care in the different phases of the palliative pathway should be addressed in nursing education and further research. In the future, investigations of patients, family caregivers, physicians and policymakers perspectives of compassionate care could present us with a more holistic understanding.

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CONFLICT OF INTEREST

There are no conflict of interest to declare.

AUTHOR CONTRIBUTIONS

All authors made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data. AST and MK conducted the interviews, AST transcribed them verbatim. All authors were involved in drafting the manuscript or revising it critically for important intellectual content. All authors have given final approval of the version to be published, participated sufficiently in the work to take public responsibility for appropriate portions of the content. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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ORIGINAL ARTICLE

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Physicians' perceptions of patient participation and the involvement of family caregivers in the palliative care pathway

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Abstract

Introduction: Patient participation is essential for quality palliative care, and physicians play a crucial role in promoting participation. This study explores physicians' perceptions of patients and family caregivers' involvement in the different phases of the palliative pathway and employs a qualitative design with thematic analysis and a hermeneutic approach.

Methods: A purposive sampling included physicians who worked in different phases of the palliative pathway. In-depth, semi-structured interviews were conducted with 13 physicians in Norway between May and June 2020.

Results: Three main themes illustrate physicians' perceptions of patients' and family caregivers' involvement: (1) beneficence for the patient and the family caregivers in the early phase, (2) autonomy and shared decision-making in the middle phase, and (3) family involvement in the terminal phase.

Conclusion: The physicians perceived bereavement conversations as essential, particularly if the pathway had been challenging. They also perceived patient participation and family caregivers' involvement as contextual. The results reveal that participation differs across the different phases of the palliative pathway. This type of knowledge should be included in the education of health-care professionals. Future research should explore elements vital to successful patient participation and family involvement in the different phases of care.

Patient or Public Contributions: Family caregivers were involved in a previous study through individual interviews. The same interview guide used for the family caregivers was used when interviewing the physicians. The family caregivers' contribution led to nuanced questions in the interviews with the physicians, questions leaning on their stories told.

KEYWORDS

advance care planning, caregivers, ethical decision-making, neoplasms, palliative care, patient, physicians

1 | INTRODUCTION

Patient participation is a core element of patient-centred palliative care,[1–4] and patients are encouraged to participate in decisions about their health care.[5–7] Patient participation and involvement are key elements of good palliative care and follow-up.[3,8–10] However, unmet needs related to patient participation and family caregivers' involvement have been reported.[3,11,12] Patient participation begins with health-care professionals' understanding their patients' preferences and needs for care, creating good relationships and exploring each patient's ability to participate, regardless of their illness and resources.[13–15] Thus, physicians should encourage patients to communicate their values and preferences and allow shared decision-making to increase their awareness and understanding of treatment options and possible outcomes.[16,17] However, primary care physicians may face challenges in end-of-life care, especially in communication and pain relief[18] because their roles are not well defined and may vary widely depending on the cases.[19]

This study examined physicians' perspectives on patient participation and family caregivers' involvement in palliative cancer care. The palliative care pathway was divided into three phases. The first phase comprised the initial days following the diagnosis of an incurable disease and began at the point where subsequent treatment was determined to be palliative. The middle phase constituted the time between the early phase and the terminal phase, and the terminal phase comprised the last weeks and days before death.[20]

1.1 | Background

Life-threatening illness is difficult for patients.[21–24] A focus on symptom relief as well as psychosocial and spiritual aspects are essential elements of palliative care.[7] Patient-centred care also strengthens patients' autonomy.[10]

Shared decision-making can improve patient and family involvement; however, physicians and health-care personnel may not be aware that participation in decision-making could be hindered or encouraged based on how they promote options or roles.[8,25] Physicians must offer patients and family caregivers an opportunity to discuss end-of-life issues.[5] Health-care providers often do not ask patients whether they want to participate, and patients do not express the kind of roles they want to play in the decision-making process.[8,25] According to Tamrisa et al.,[26] most physicians prefer honest and open communication when discussing patients' concerns and expectations, whereas others choose to adhere to treatment protocols, without explaining the alternatives in the belief that they are giving patients false hope.[27]

Patients who want to be involved and play an active role in the decision-making process may find it challenging when decisions are delayed and alternative treatment options are not discussed.[1,26] Several communication gaps have been identified in cancer care, including shared decision-making, unmet needs, open communication[28] and the opportunity to be heard without being judged.[29] Inadequate information provision, lack of practical guidance and insufficient support from health-care professionals are other challenges.[30] Essential competencies for patient and family satisfaction include prognostication, conflict mediation, empathic communication and family-centred care.[9]

Family caregivers play a critical role in the decision-making process, with patients often taking the final decisions after consulting with their family caregivers.[31] While patients, their families and health-care professionals may have different views on prioritizing the different palliative care dimensions,[32] they need to cooperate to contribute to the patient's wishes and needs.[3] It is also essential to initiate end-of-life care early because delayed communication may lead to missed opportunities.[33,34]

Advance care planning (ACP) and general practitioners' (GPs) involvement have improved palliative care. GPs are central in introducing ACP; simultaneously, GPs have also reported difficulties in introducing ACP when patients are receiving treatment in a hospital.[35] Introducing ACP can be an autonomous decision, as some patients may not be willing to have that conversation.[36] Furthermore, family caregivers report a lack of involvement in and preparation for the dying process.[12] Thus, there is a gap between the guidelines and the emotional and psychological support received in palliative care.[12,33,37]

In all the three phases of palliative care, the patients are primarily at home, which is recommended.[38,39] In home-based care, patients and family caregivers rely on GPs and nurses' medical proficiency, availability, person-focused approach and proactiveness.[13,40,41] The home-based care provided by physicians and contracted professionals outside the family could also effectively support home deaths.[42,43]

We believe that greater insight into palliative care participation will be useful in improving care. As physicians play a key role in ensuring quality palliative care and promoting patient and family involvement, we examined how physicians perceived patient participation and family involvement in the different phases of the palliative care pathway.

1.2 | Ethical principles and theoretical framework

We applied the four principles of biomedical ethics[44] and the approach of Thompson et al.[45] to explore patient participation. These ethical principles and the theoretical framework of patient participation were appropriate and were used as theoretical lenses in the analysis.

Four principles of health care that form a moral framework are highlighted[44]: (1) Respect of autonomy: refers to respecting the decision-making capacity of autonomous persons and their right to participate, ensuring informed consent in important decisions. Therefore, the health legislation's provision on consent competence might be necessary to practice autonomy. This principle obliges disclosing information to probe for and ensure understanding and voluntariness, and to provide adequate decision-making; (2) Non-maleficence: refers to protecting against unnecessary harm. Assessment and treatment are burdensome and can involve a health risk.

Therefore, the risk of injury should be less than the expected benefit of examinations, treatment, and other healthcare; (3) Beneficence: refers to providing benefits and balancing benefits, burdens and risks. One ought to prevent and remove evil or harm. One ought to perform and promote good. In addition, beneficence balances the utility value and benefits of treatment choices against the risk and strain to which the person is exposed; and (4) Justice: refers to fairness in the distribution of benefits and risks. It is about the management and distribution of opportunities, health benefits and resources. Costs and resources should be distributed in a fair way and managed with the intention to treat cases equally.[44]

We used five levels of involvement that ranged from non-involvement to full autonomy, based on the framework of Thompson et al.[45] Participation comprised five components: (1) contributing to action sequences, (2) influencing the problem definition, (3) sharing the reasoning process, (4) influencing decision-making and (5) experiencing emotional reciprocity. They were in turn based on three core elements: components, levels and context.

A patient's participation depends on the context and may change during their illness. The health-care provider has a responsibility to promote patient participation through dialogue and information sharing.[44,45]

1.3 | Research question

This study's research question was: How do physicians perceive patient participation and family caregivers' involvement in the different phases of the palliative pathway?

2 | METHODS

2.1 | Design

The study employed a qualitative design using thematic analysis[46,47] and a hermeneutic approach.[48,49] Interviews were based on open-ended questions,[50] and the consolidated criteria for reporting qualitative research checklist was used to complete the reporting.[51]

2.2 | Participants

Thirteen Norwegian physicians treating palliative care patients were recruited through purposive sampling.[50] Both palliative care physicians and GPs treating palliative care patients with cancer were included. The inclusion criteria were physicians with experience in palliative care and treating patients and family caregivers using primary care services. A contact person in health care recruited the physicians. Although 15 physicians were approached to participate, only 13 were accepted. Their demographic characteristics are summarized in Table 1.

TABLE 1 Demographic data

Demographic data	Participants (*N* = 13)
Gender	
Men	10
Women	3
Age (years)	
41–50	7
51–60	4
61–70	2
Workplace	
Hospital	6
Primary care	7
Experience as a physician (years)	
10–15	2
16–20	5
21–25	0
26–30	4
>30	2

TABLE 2 Interview guide

Can you tell me how you experience palliative care?
How are patients and family caregivers involved in the different phases of the pathway?
What is important when communicating with patients and family caregivers in different phases of the palliative pathway?
In your experience, what kind of information is important to communicate?
How do you wish to collaborate with family caregivers throughout the pathway?
What is important about the nature of the care offered in different phases of the palliative pathway?
What challenges and ethical dilemmas did you experience?
Do you want to add something else?

2.3 | Data collection

The interviews took place from April to May 2020 and were conducted by the first author. Owing to the COVID-19 pandemic, all the interviews were performed individually through video meetings.

An interview guide with open-ended questions (Table 2) was developed based on the study's aim and previous research.[12,20,50] The questions focused on how physicians perceived patient participation and family caregivers' involvement in the palliative pathway. The interviews lasted between 35 and 60 min.

When the interviews produced no new information, the authors discussed the possibility of saturation, and found the data to be rich and dense, and saturated with preliminary themes.[52,53]

2.4 | Data analysis

The interviews were audio-recorded and transcribed verbatim by the first author. All the authors read the interview transcriptions to gain a holistic impression of the data.[50]

A thematic analysis and the six steps of Braun and Clark[46,47] were used to analyse the data. First, all the authors read and reread the transcribed interviews and noted their initial ideas. We also discussed their overall understanding of the data set's coding phases. The first author coded the interviews related to participation in the early, middle and terminal palliative care phases. Second, the authors constructed a coding tree guided by the four ethical principles (i.e., autonomy, nonmaleficence, beneficence and justice)[44] and the involvement perspective of Thompson et al.[45] Third, the authors identified key quotations. In the fourth step, the authors discussed subthemes and themes. The analysis was inductive as well as deductive. We worked back and forth between the subthemes and themes until we had established a comprehensive set of themes. Then deductively, we looked back at the data from the themes to determine if more evidence could support each theme. Then the subthemes were abstracted into three main themes, which illustrate physicians' perceptions of participation in the different phases of the palliative pathway. In the fifth step, the authors validated the naming of the themes through communicative validity.[50] In the last step, the first author wrote down the results, based on feedback from the other authors.

The analyses employed a hermeneutic approach, recognizing the influence of preunderstanding on data interpretation.[49] We developed a new understanding through group discussions in which all the authors were engaged.[50] The first author has worked as an oncology nurse in primary care for 10 years. Leaning on a hermeneutic approach, her preunderstanding influenced data interpretation.[49] The hermeneutic circle conveys the meaning that the parts depend on the whole and the whole depends on the parts.[48,49] Thus, we developed a deeper understanding of physicians' perceptions of patients and their family caregivers' involvement in the different phases of the palliative pathway. In a hermeneutic approach, the researcher is a participant and producer of knowledge as the data are collected, analysed and interpreted.[49]

2.5 | Ethical considerations

The project adhered to the guidelines for research ethics laid down by the Declaration of Helsinki. The study was considered by the ethics committee and did not need approval.

All the physicians were given oral and written information on the study and could withdraw at any stage. The first author obtained written informed consent from participants before the interviews. All data were anonymized.

3 | FINDINGS

Thirteen physicians were interviewed (Table 1). Three themes related to the different phases in the palliative pathway were identified: (1) beneficence for the patient and the family caregivers in the early phase, (2) autonomy and shared decision-making in the middle phase and (3) family involvement in the terminal phase.

3.1 | Beneficence for the patient and family caregivers in the early phase

3.1.1 | Emotional reciprocity

The physicians described the early phase as demanding for both patients and family caregivers. Patients in this phase were affected by the side effects of treatment, weakened general conditions and loss of roles. Physicians reported that the patients needed to be informed about the transition from curative to palliative treatment options and what they could expect from such options. In this phase, information should meet the patients' and family caregivers' emotional needs: 'Getting cancer is terrifying and dying is difficult; we all want to live' (13). The physicians wished that providing information in this phase should contribute positively to the process of preparing for death, listening and creating openness. Those involved in the treatment need to discuss matters with each other to coordinate information with the patient and their family caregivers. The physician expressed a paternalistic attitude; however, they considered it important to establish a close therapeutic relationship with patients and their family caregivers. Ideally, they conveyed that they preferred to give information to patients and caregivers simultaneously.

3.1.2 | Physicians' treatment choices

The physicians assumed that patients and family caregivers lacked the required medical knowledge to participate in treatment choices and emphasized their responsibility as physicians: 'We must understand that it is our responsibility to choose the best treatment. It creates insecurity if the patient has to choose their treatment' (13). This shows that the physicians were concerned with doing what they thought would benefit the patient and family caregivers.

The physicians considered compassionate care, including information and dialogue essential in the transition from curative to palliative treatment. According to the physicians, this could be a sliding transition, where patients' understanding of their treatment could occasionally be incompatible with professionals' understanding. The physicians acknowledged that they were sometimes unsuccessful in informing patients about the transition from curative to palliative treatment. The physicians expressed that ideally, both patients and family caregivers should be involved in this process.

3.1.3 | Creating security for patients and family caregivers

The physicians conveyed that it is important for patients and family caregivers to know who was responsible for the treatment, the physicians in the hospital or the GP: 'It is important that family caregivers are well informed and included in decisions about who will follow-up' (3). To create a sense of security for patients and family caregivers, they emphasized the importance of constructing a palliative care plan. Physicians also told it necessary to communicate the point of contact in case the illness worsened, or other potential medical challenges were encountered.

The physicians were also concerned about ethical dilemmas associated with providing information. They considered the needs of patients and family caregivers, which had to be adapted to patients' health literacy as essential. The physicians also saw it necessary to provide individualized information. Information and dialogue with family caregivers were seen as essential for planning a good course of treatment. The physicians also noted potential challenges in predicting family caregivers' care resources in the palliative care process.

The physicians emphasized their duty of confidentiality towards the patient. It was vital that the patient decided how and to what extent family caregivers could be involved. Some patients did not want the information to be passed on to their family caregivers. This might be an ethical dilemma for the physicians. Some of them said that they urged patients to inform family caregivers based on their best interests.

3.2 | Autonomy and shared decision-making in the middle phase

3.2.1 | Patient and family caregivers' involvement

According to the physicians, the middle phase could be a comparatively calmer period in which the patient and family caregivers prepare for the death. Patient autonomy was considered particularly important: 'It is the patients who own this process' (8). The physicians considered that ACP was a good tool. It was essential to have conversations with the patient and family caregivers about the pathway, their future expectations and their thoughts regarding participation. The physicians highlighted challenges in meeting patients' and family caregivers' differing needs for information and involvement in the treatment and emphasized the need to be open about the disease's progression and include patients and family caregivers in discussions about possible future challenges and choices that would have to be made: 'I experience that most people prefer to have an open and good dialogue. They are grateful after the difficult conversation' (12). In the interviews, there was a lack of reflections on how patients and family caregivers experienced ACP.

3.2.2 | Continuity of care

The physicians emphasized that building trust was important. One GP explained how he actively worked to create trust and security by having routine consultations with patients: 'I think being assigned appointments regularly makes it easier for the patient, and they do not feel that they are taking my time. I am the one who gives the time. If they do not want the consultation, they actively cancel' (8).

The physicians felt it would be easier to outline responsibilities and create security if patients did not constantly have to deal with new health-care personnel in the hospital and the municipality. Information could be overlooked if there was not enough confidentiality around crucial conversations.

The physicians working in palliative teams emphasized the importance of working in multidisciplinary teams. They highlighted that the nurses often had an important role in coordinating the care and the treatment.

3.2.3 | Family caregivers as resources

The physicians highlighted family caregivers as a crucial resource in palliative care and emphasized the need to spend time with them. The closer the patient was to the terminal phase, the greater the need to cooperate with family caregivers. Close cooperation was also crucial when death at home was planned: 'Family caregivers must be in place. It is so easy and so difficult at the same time' (7).

Security, accessibility, information and planning for the time ahead were viewed as essential components of care. Physicians cited examples of family caregivers who mobilized help to ensure that the patient was adequately cared for, as providing care entailed considerable responsibility. As family caregivers have different levels of resources, physicians were often concerned about the adequacy of resources, although family caregivers often mobilized more resources than they expected.

3.3 | Family involvement in the terminal phase

3.3.1 | Early involvement of family caregivers

The physicians highlighted how, in the terminal phase, they tried to support family caregivers emotionally and identify common perspectives and solutions. Family caregivers' involvement in the palliative pathway was akin to living the grieving process: 'The most important thing we can do to help them cope with their grief is what we do along the way. If we did a bad job, a bereavement conversation will not save the grieving process' (9). Family caregivers should feel validated, heard and respected throughout. In this process of understanding, having a plan for what may lie ahead was an essential issue.

Some physicians said they had become better at involving the family caregivers, emphasizing that this has led to people increasingly declining a bereavement conversation. One of the physicians said he could tell who would need a bereavement conversation based on how stressful the palliative pathway was and whether the family caregivers considered the death as traumatic. Providing information to the family caregivers about how they could experience the time after their family member's death was essential in supporting the mourning process.

3.3.2 | Autonomy maintained by family

In the terminal phase, the family often maintains the patient's autonomy. The physicians depend on the information provided by family caregivers to consider the patient's interests. Physicians said it was essential to clarify with the patient, early in the pathway, that the physicians would contact family caregivers when the patient was tired or otherwise indisposed.

Family caregivers were described as a link between the patient and the physicians; thus, a good relationship with family caregivers was vital: 'We used to support the family caregivers and help them understand. Sometimes the symptoms bother the family caregivers more than they do the patient' (2). Additionally, regular follow-ups and a continuous flow of information provision were necessary to satisfy family caregivers' concerns. Some patients may find relief in letting family caregivers play a more prominent role. Physicians also noted family caregivers' fear of not being able to adapt to progressive disease symptoms and not being able to cope with a worsening situation. The terminal phase could be challenging regarding symptom relief and the level of care required from family caregivers.

3.3.3 | Bereavement conversations

The physicians said conversations with the bereaved after the patient's death were important for processing the challenging experiences during the pathway: 'If there had been complicated processes and stress about treatment clarifications regarding symptom relief, the physicians might be involved in the bereavement conversation' (12). A bereavement conversation could help summarize the challenging events and provide answers to questions that had remained unanswered. It was also an opportunity to discuss possible feelings of guilt. They highlighted the importance of bereavement conversations to avoid lifelong trauma; half an hour of bereavement conversation could prevent the bereaved from developing dark thoughts for the rest of their lives.

The physicians viewed bereavement conversations as positive and were often conducted in a friendly atmosphere. They experienced that the bereaved often seemed lighter in spirit after such conversations.

4 | DISCUSSION

In this study, patient participation and family caregivers' involvement has been studied from the perspective of physicians. The interviews gave rich and thick descriptions of physicians' perceptions of patient and family caregivers' involvement in the different phases of the palliative pathway. The result might be interpreted as the physicians expressed that the ethical principle of beneficence characterized the first phase. The principle of autonomy and shared decision-making characterized the middle phase. Family involvement was considered crucial in the terminal phase. This study offers new insight into physicians' perceptions of patient participation and family caregivers' involvement in the different phases of the palliative pathway.

The physicians perceived an ethical dilemma between beneficence and patient autonomy. They saw the importance of balancing the burden and risks for the patient and the family.[44] The physicians considered it their responsibility to choose the best treatment for the patient, this might be seen as an ethical dilemma in relation to safeguarding the patient's autonomy.

It is clear from the physicians' accounts that finding a balance between the different ethical principles[44] is a process that evolves over time and requires competence and practical experience in the field of palliative care. The principle of autonomy emerges as a common thread that runs through the entire palliative process, modified by the principle of beneficence, especially in the early stage of the palliative pathway and in the involvement of family caregivers. Physicians balance the two principles of beneficence and autonomy, especially information and communication in the early phase. Balancing communication within participation depends on how much patients can and want to participate and the context,[44,45] as well as their individual preferences.[26] The physicians also discussed family caregivers' involvement and the balance between autonomy and the principle of nonmaleficence. Family caregivers often have a say in autonomous decisions[31] even when their needs or wishes differ from those of the patient.[32]

Extant research has indicated the importance of the coordination and integration of care and information and communication as primary goals. Emotional support and the involvement of the family are vital.[3,8,10] The physicians expressed that beneficence was important for the patient and the family caregivers early in the pathway.

We found differences among physicians in how they viewed the decision-making process. Sometimes they prioritized autonomy and encouraged a high degree of patient involvement, while at times, they had a mildly paternalistic attitude. Thompson et al.[45] demonstrated how involvement differs in terms of context, levels and components. In our findings, physicians made some treatment choices to avoid unnecessary risks to the patient. This is consistent with previous findings.[16,44] The physicians in our study highlighted patient autonomy, especially in the middle phase, although this could conflict with the ethical perspective of beneficence to the family caregivers.[44] Extant studies found that patient-centred care could be at the expense of family caregivers, who tend to be neglected.[12,32,37]

We found that physicians are aware of the significance of involving the patients and family caregivers. In contrast, prior studies have shown that physicians do not meet the patient's and family caregivers' information needs.[1,26,28,29] The physicians in our study also discussed a shift in autonomy from the patient to the family caregivers, in which they played an active role in helping patients hand over the authority to make choices to the family caregivers—doing good to the patient was the reason for this initiative.[44] Previous research has also indicated limited involvement of family caregivers and a lack of preparation for the terminal phase.[12,33] This lack of participation does not correspond with our results; indeed, experienced physicians acknowledged the importance of their involvement throughout the pathway. In the mentioned studies, however, it is a clear finding that physicians and family caregivers emphasize the importance of cooperation and involvement in the first phase.[12]

Our study confirms ACP's significance, which includes patients and family caregivers in planning palliative care. Many of the physicians highlighted the importance of formulating a plan to ensure safety and predictability for the patient and family caregivers, which is consistent with earlier research emphasizing ACP's importance early on in the pathway to promote predictability.[3,20,35] Research shows that the concept of quality in palliative care has to be familiar to patients, family caregivers and health personnel,[32,35] and highlight patients and caregivers' unmet needs, especially regarding communication with health-care professionals.[28,37] The physicians in our study mentioned the importance of building trust with both the patient and the family caregivers to include them in discussions about the future and formulate plans.

They considered family caregivers as a resource for the patient throughout the pathway. This finding is consistent with Lamore et al.[31] who revealed the essential role of family caregivers in the final decision-making process. Family caregivers' early involvement in the pathway was also highlighted in the Lancet Oncology Commission.[3] The physicians noted that involving family caregivers early in the palliative care pathway and ensuring that they closely monitored the process led to better grief processing. Many believed that the need for bereavement conversations had diminished, reflecting an increase in family caregivers' involvement and adaptation.

4.1 | Strengths and limitations

One of the strengths of this study is the physicians' long-term experience in palliative care. The physicians were both men and women of various ages, worked in primary and specialist care, and were from both rural communities and larger cities, and from local and regional hospitals. Gender analyses were not in focus in the study. Men and women participated in the study because we wanted variation and, our theoretical perspectives do not focus on gender. Although this study was conducted in Norway, the findings may be transferable to other countries with similar health-care environments.[54]

A limitation might be that the first author has worked as an oncological nurse in primary care for 10 years, and has a preunderstanding. However, all the authors collaborated in the interpretation and development of a shared understanding of the data, ensuring a holistic perspective.[49,50,54] Additionally, the theoretical framework[44,45] strengthened the transparency of the interpretation.[54]

Observations in addition to interviews could have been applied to collect data.[45] Method triangulation in further research might be valuable to develop a more comprehensive, consistent and coherent understanding of how patient participation and family involvement occurs in practice.

4.2 | Implications

This study provides insight into the complex concept of participation and the four ethical principles: autonomy, beneficence, nonmaleficence and justice. The dilemma expressed by physicians between ethical principles and encouraging patient participation and family caregivers' involvement can be transferable to patients with incurable diseases. The results reveal a need for physicians to see participation as a contextual process, which should be a topic in further specialist and medical education. In addition, future studies should determine the factors that are essential to successful patient participation and family involvement in palliative care. Future research should give more attention to the way doctor–patient communication is incorporated into the multidisciplinary palliative care plan.

The physicians in this study involved the family caregivers early and throughout the palliative pathway; this should be highlighted in health personal education and future research. In addition, the conflict in balancing ethical principles and the consequences for clinical work should be highlighted, both in daily practice and in further research. In the future, investigation of patients and family caregivers, as well as nurses' and policymakers' perspectives on participation, involvement and ethical principles, could present a more holistic understanding for all, including researchers and other stakeholders.

5 | CONCLUSION

The physicians perceived that patients' participation and family caregivers' involvement differ across the various phases of the palliative pathway. The ethical principle of beneficence for patient and family caregivers is seen as most important in the first phase. In the second phase, the physicians saw autonomy and shared decision-making as crucial. In the terminal phase, the physicians perceived family involvement as essential. The physicians were concerned with patient participation and family involvement throughout the palliative pathway. The study showed that the physicians perceived patient participation and family caregivers' involvement as contextual and that participation differs across the different phases of the palliative pathway.

AUTHOR CONTRIBUTIONS

Anett Skorpen Tarberg, Torstein Hole, Morten Thronæs, Marit Kvangarsnes and Bodli Landstad designed the study. Anett Skorpen Tarberg collected the data. All authors contributed to the analysis and interpretation of data. Anett Skorpen Tarberg and Torstein Hole drafted the manuscript. All authors have contributed to revising this article critically and contributing with important intellectual content. All authors agreed to be accountable for all aspects of the work.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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