Quality and safety in hospital cancer care

A mixed methods study of next of kin involvement

by

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Summary

Introduction: Next of kin involvement in cancer care services is complex, challenging and influenced by factors related to the organisation of the healthcare service, the resources of the next of kin, and the patient's ability to cope with treatment and care.

As the provision of cancer care services has changed from in-patient wards to out-patient clinics, next of kin involvement practice faces new challenges. As the roles of healthcare professionals and of patients are regulated by law, the formal expectations of the next of kin role are low in Norway. However, changes in the organisation of cancer care services bring a new perspective to the role of next of kin.

The Ministry of Health Care Services requires healthcare services to acknowledge the next of kin's need for relief, involvement, and contribution to patient care. Less is known about how to facilitate and adapt to these changes. Research confirms that next of kin involvement is a key factor in keeping a patient safe during the cancer care trajectory, but there has been little discussion of the best way to involve the next of kin.

This PhD thesis addresses the lack of knowledge on next of kin role for quality and safety in hospital cancer care, and the need for methods and tools for next of kin's systematic involvement in these services.

Aim: The aims of the study were to explore the role of next of kin for quality and safety in hospital cancer care, and to develop a consensus-based guide for next of kin involvement in hospital cancer care. The objectives were:

- to map next of kin involvement and methods used in two hospitals from the managers' and healthcare professionals' perspective,

- to explore next of kin satisfaction with cancer care services and suggestion for next of kin involvement from the next of kin perspective,
- to synthesise finding and explore topics and elements relevant for a next of kin involvement guide to support quality and safety in hospital cancer care.

Methods: This study has utilised a mixed methods case study design, with a mixed methods convergent design at its core, including 1) a multiple embedded case study with managers and healthcare professionals (n=32) within cancer care departments in two University hospitals in Norway; 2) mapping of next of kin experiences with a questionnaire survey measuring their satisfaction with cancer care in the same two hospitals (n=238); and 3) conducting a modified Nominal group technique consensus process with a stakeholder groups (n=20) from both hospitals and next of kin representatives. The findings were integrated into a guide for next of kin involvement in hospital cancer care.

Results: Paper I reports findings from a comparative multiple embedded case study of cancer departments in two Norwegian university hospitals. The aim was to explore how managers and healthcare professionals understand the role and contribution of next of kin in cancer care, and what methods they used to involve next of kin. Data collection consisted of analysis of national policy documents, and interviews with managers and healthcare professionals collected in 2016. Results showed that although healthcare professionals in both hospitals depended on next of kin collaboration throughout the care process, only a few systematic approaches to involvement were found. Managers and healthcare professionals in both hospitals insisted on a need for more guidance for next of kin involvement in hospital cancer care. This paper illuminates nine areas in which next of kin are important to quality and safety in cancer care: information, pain treatment, transitions, observations,

motivation, emotional support, physical activity, rehabilitation, daily care, nutrition, palliative and terminal care.

Paper II reports findings from the same comparative multiple embedded case study as in paper I. Data collection was the same, but the data was analysed by directed content analysis according to Hollnagel's four potentials for resilient performance (respond, monitor, anticipate and learn). The results showed how next of kin are co-creators of resilient performance in hospitals. They complemented healthcare professionals in all four potentials for resilient performance.

Paper III reports findings from a mixed methods convergent design study. Responses were collected from 238 next of kin between November 2016 and November 2017. The aim was to explore next of kin satisfaction with hospital cancer care and to use the results as a basis for improving quality and safety in hospital cancer care. The paper applied the 20-item FAMCARE scale as a survey instrument. Open-ended questions were used for qualitative analysis. The paper combined regression analysis, exploratory factor analysis and qualitative content analysis. Results showed that next of kin in both hospitals reported high satisfaction with care. In general, results showed a higher score on satisfaction with care (1.5,1.1-2.0), $p < .001$ (Wilcox signed test) than with involvement related items. This indicates a lack of systematic approaches and sound methods of involvement to improve satisfaction and service quality and safety. The largest difference between the case hospitals was found in item Q15 ("The way the family is included in treatment and care decisions"), with a 30% increased probability of being satisfied or very satisfied at hospital 1 (RR 1.3, 95% CI 1.1-1.7, $p = .013$). The synthesis of the mixed methods results of this study disclosed that next of kin should be acknowledged as an independent part in the healthcare team around the patient, and not merely as part of the patient's role.

Paper IV reports findings from a participatory consensus method based on a modified Nominal group technique process applied as a single one-day meeting with 20 stakeholder participants. The overarching research problem for the meeting was: *What topics or elements should be included in a next of kin involvement guide to support quality and safety in hospital cancer care?* This paper integrates agreed upon topics of next of kin-related challenges in hospital cancer care by presenting a guide development for use in clinical practice. The results showed key topics and elements designed for managers and healthcare professionals in the cancer care setting to guide improvement initiatives for quality and safety. The panel emphasised the importance of building systems for gathering experiences from next of kin, incorporate and use experiences for service improvement, tailor next of kin training, and support and create a culture that considers next of kin involvement as a prerequisite for sound patient care. The paper results in the *Next of Kin Involvement Guide*. The guide builds on the Organizing for Quality framework [1] and is adapted to the cancer care setting by integrating the key topics from the consensus process.

Conclusion: The thesis has demonstrated that next of kin hold a vital role for quality and safety in the cancer care in the two case hospitals (e.g. transitions, palliative care, pain treatment, motivation, daily care). It also disclosed that hospital cancer care lacked systematic next of kin involvement in the organisation of healthcare services. In addition, tools and guides for sound next of kin involvement were missing. By identifying suggested methods for involvement (e.g. system improvement, user surveys, one appointed healthcare professional for the next of kin, closer interaction with support bodies) from the managers', healthcare professionals', and next of kin' perspectives, and by integrating these into the Next of Kin Involvement Guide (Figure 5.), the thesis contributes with a requested tool that has the potential to support managers' and healthcare professionals' future working on quality and safety in hospital cancer care.

Table 1 Thesis at a Glance

	Paper I	Paper II	Paper III	Paper IV
Research questions	How are next of kin involved in hospital cancer care? How do managers and healthcare professionals perceive challenges in next of kin involvement in cancer care?	How are next of kin involved in shaping resilience within cancer care in hospitals? (Paper II)	What are the similarities and differences in next of kin satisfaction with cancer care in two Norwegian hospitals? How would next of kin like to be involved in cancer care in two Norwegian hospitals?	What topics and elements should be included in a next of kin involvement guide to support quality and safety in hospital cancer care?
Method	Comparative multiple embedded case study of cancer departments in two Norwegian university hospitals where the aim was to explore how managers (13) and healthcare professionals (19) understand the role of next of kin in cancer care, and what methods they use for next of kin involvement.	Comparative multiple embedded case study as in paper I. Data collection was the same as for Paper I, but the data was analysed by ways of a directed content analysis according to Hollnagel's four potentials for resilient performance (respond, monitor, learn, anticipate)	Questionnaire study with responses from 238 next of kin with a mixed methods convergent design applying the 20-item FAMCARE scale as a survey instrument, and open-ended questions used for qualitative analysis.	Participatory consensus-based process based on a modified Nominal group technique applied as a single one-day meeting with 20 stakeholder participants.
Results	Healthcare professionals in both hospitals were dependent on next of kin collaboration throughout the care process, however only a few systematic approaches for involvement were found. Managers and healthcare professionals in both hospitals argued that there is a need for more guidance for next of kin involvement in hospital cancer care.	The results showed how next of kin were co-creators of resilient performance in hospitals and complemented healthcare professionals in all the four potentials for resilient performance (respond, monitor, anticipate and learn).	The synthesising of the mixed method results showed in general high next of kin satisfaction with hospital cancer care: The study also disclosed that next of kin should be acknowledge as an independent part in the healthcare team around the patient, and not merely as part of the patient's role.	The panel emphasised the importance of building systems for gathering experiences from next of kin, formally integrate and use experiences in a feedback loop for service development, tailor next of kin training and support and create a culture that considers next of kin involvement as a prerequisite for sound patient care.

Abbreviations

CAS: Complex adaptive systems

CI: Confidence intervals

OECD: Economic Co-operation and Development

NPE: Norwegian System of Patient Injury Compensation

RR: Relative risks

RHA: Regional health authority

SD: Standard deviation

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Part I

1 Introduction

This thesis explores the role of next of kin and its contribution to quality and safety in hospital cancer care. It provides new knowledge from the next of kin`s perspective as well as from healthcare professionals' and managers.

1.1 Cancer in Norway

In 2018, 283 984 people in Norway were living with a cancer diagnosis and 34 190 new cancer cases were diagnosed [2]. The four largest diagnoses group, accounting for nearly 50% of all new cases, are prostate, breast, lung, and colon cancer. More males than females are diagnosed with cancer [2]. The incidence of cancer is higher in Norway than the average of the 36 OECD countries, but the cancer mortality is lower [3]. The number of cancer cases in Norway has increased steadily over the last 20 years. The increase is due to several factors such as increased population, a growing elderly population, earlier and improved diagnostics, screening programmes, and increase in diagnoses of certain cancers [4]. The rate of cancer survival is also rising, so people with cancer are living longer. This creates new challenges and strains for the healthcare system [2].

1.2 The Norwegian healthcare system

The Norwegian healthcare system is financed through public budgets. All residents are covered by the National Insurance Scheme. The system builds on universal access to healthcare services. There is a free choice among public financed providers and hospitals. Norway has four regional Health Authorities that provide healthcare services within their districts, but the government is responsible for the financial coverage [5].

In the Norwegian welfare state, healthcare is recognised as a public responsibility. The model builds on individual rights, and a presumption that next of kin participation as welfare providers should not be a statutory obligation [6]. Nevertheless, even if the formal expectations for participation from next of kin are low, the reality is that the state depends on support from the next of kin [7]. Numbers indicate that nearly 50% of all care is done by next of kin [8]. The government has acknowledged this and started to bring more attention to the next of kin role, highlighting that next of kin are important stakeholders for the patients and for healthcare services. They should therefore be more involved and acknowledged [9]. The rationale for this change in next of kin policy is to build an alliance between families, voluntary organisations, and healthcare services [8].

1.3 Trends in organisation of cancer care services

In 2020 the World Health Organization estimates that cancer is responsible for one in six deaths globally, and the number of cancer cases continues to rise. These global trends has resulted in recommendations for faster clinical evaluation, diagnoses, staging and access to high quality cancer treatment and care [10].

The Norwegian government's ambition for cancer care in Norway is to create "the patients' healthcare services." The goal is to create a more user-friendly cancer care service, to be a pioneer in cancer care provision and prevention, ensure higher and prolonged survival with the best possible quality of life for these patients and their next of kin. The trend in organisation of cancer care in Norway is that diagnosis, treatment, and care provided by the hospitals are more predictable, personalised and faster [4]. Between 2013 and 2017, the government created 28 care pathways for standardisation of cancer care organisation, diagnosis and treatment in Norway [4]. It is a national goal to have 70% of all patients with a potential cancer diagnoses included in care pathways, and 70% of

these should complete the pathway within the designated time frame [11].

A typical course for a patient with suspected cancer in Norway is to consult their general practitioner (GP). The GP refers the patient to the hospital. The patient is then placed in a care pathway for cancer followed by rapid essential tests, requirements and meetings leading to a diagnosis. After diagnoses the patient is appointed a cancer coordinator in the municipality. This arrangement (coordinators) is financed by the Norwegian Cancer Society. Cancer treatment and care in general are paid for by the public sector and the patient is followed up by the hospital and the GP. There are also opportunities for a patient to pay for private services. The patient is followed closely by the hospital during the cancer treatment, however several actors in the healthcare system are involved in the care of the patient depending on care needs which again depend on the diagnoses and treatment responses. The municipalities are responsible for the primary healthcare services (GP, nursing homes, homecare services, emergency clinic). The hospitals are state owned and part of a local health trust, subordinate to a reginal health trust reporting to the Ministry of Health and Care Services. The cancer patient will alternate back and forward between these service levels (hospital, municipalities) in the trajectory, but the division of tasks is not always seamless from the patient and next of kin perspective [12]. Since the data collection was done for this study several care pathways have been introduced in the hospitals with additional quality indicators [4].

There has been an organisational change in hospitals, with more treatment provided by outpatient clinics and there are signs that the change can create an offset of caregiver responsibility towards more involvement in care for the next of kin [13, 14]. Consequently, the next of kin may take on tasks that they are not prepared to handle, resulting in greater stress when care demands exceed the resources, capacity and interest of the next of kin [15].

Institute of Medicine (USA) has identified next of kin as an important quality and safety dimension in patient-centred care, especially for providing individualised care services [16]. In Norway, there are indications that next of kin will have a stronger voice as agents of quality and safety [17].

1.4 Adverse events in cancer care

A nationwide study from Sweden (2016) shows that the risk of adverse events for cancer patient is seven times higher around the period of diagnoses (e.g., infections, bleeding). However, the study also shows that the risk increases markedly, not only caused by complications or wrong treatment, but also by self-inflicted harm caused by adverse events [18].

A recent PhD study from Norway investigating adverse events in hospitalised cancer patients, found that cancer patients experience more adverse events than other hospital patients due to older age, longer hospital stays, and surgical challenges and complications [19, 20]. The study also highlights that potential risks of concern for cancer patients in hospitals are related to medication harm and infection [20]. Among cancer patients dying in hospitals, the rate of severe adverse event is as much as seven times higher than the general population of hospitalised patients [20].

Risk of cancer treatment is described as high in Norway and potential threats to safety in the cancer care process are detected in relation to surgical challenges and complications, deaths, and information failure that lead to proposed or wrong diagnosis [21]. Numbers from the Norwegian System of Patient Injury Compensation (NPE) show that cancer is the second largest medical area with reported cases in Norway. Common reasons for compensation in the cancer field are failures in treatment or diagnosis [22].

Next of kin involvement is also on the agenda in relation to risk in cancer care in Norway [21]. Hannisdal and colleagues have identified 16 most common safety risks for cancer patients in Norway [21]. Failure in patient communication and lack of involvement of next of kin is a risk recognised as very likely to happen weekly [21]. The latter indicates that there is a correlation between the safety of cancer patients and next of kin involvement that should be explored further. This thesis will address the gap in knowledge on how involvement of next of kin can contribute to quality and safety in hospital cancer care.

2 Background

2.1 Next of kin involvement in hospital cancer care

Next of kin involvement has become an essential part of service development and everyday work in hospital cancer care [23, 24]. Next of kin involvement is complex, challenging and influenced by several factors related to the organisation of the healthcare service, the resources of next of kin, and the patient's ability to handle treatment and care [25, 26].

Next of kin are often the first to note changes in a patient's situation in all phases of the cancer care trajectory [27]. The next of kin often feel responsible for meeting the patient's everyday needs for care, medicine compliance, rehabilitation, and for monitoring technical procedures or equipment such as infusion pumps or central lines [28-30].

Research shows that the next of kin's need for involvement, acknowledgment and care is often overlooked by healthcare systems [31-33]. When next of kin lack knowledge and training in basic skills required for individual patient's needs, it can cause uncertainties and worry, leading to longer hospital stays [34]. Compiling experiences and supporting the next of kin throughout the trajectory can enhance the patient's ability to cope with treatment and care [35]. Research in the field of next of kin involvement in hospitals is fragmented, and there is arguably a need for mixed methods studies with larger samples [13].

2.2 Methods and tools for next of kin involvement

The cancer care field is described as one of the most common areas that requires assistance from the next of kin [36, 37]. Next of kin often have a unique role in the cancer field and several features distinguish cancer caregiving from other chronic illnesses: rapid health deterioration,

variability in symptoms, the need for advanced monitoring skills, and complicated treatment regimens that require decision-making [38, 39]. The next of kin of a patient with cancer is often required to adapt and respond quickly to an uncertain disease over a longer span of time [32].

A scoping review from 2018 found three categories of methods or tools for next of kin involvement in hospital care of cancer patients: 1) participation in direct care (e.g., comprehensive care, helping the patient and healthcare professionals); 2) emotional support (e.g., protecting, supporting and visiting the patient); and 3) participation in care decisions (e.g., acting as an advocate, participating in discussions of decision-making and end-of-life decisions) [13]. Another study found that the most effective interventions to decrease caregiver strain were training and skill development; couples therapy; decision support/decision aids; multicomponent interventions and palliative care [15].

Nevertheless, there is significant evidence that the effect of these methods and tools (e.g., courses, education, discharge support, surveys) is indistinct [15, 40]. The focus has until now been on methods and tools to support next of kin, and there is a lack of knowledge on how to involve next of kin in care to enhance the quality and safety of cancer care services. Research in this field reflects the complexity of studying next of kin involvement, and the next section elaborates on those challenges, consequences, and possibilities. Even with effective methods and tools, research emphasises the importance of identifying new interventions for involvement of the next of kin in cancer care, designed to ensure uptake by both patient, next of kin, and healthcare providers [15, 27, 41, 42].

2.3 The complexity of next of kin involvement

Care provision can cause psychological burden and physical distress for the next of kin [33]. Thus, the next of kin have an increased risk of developing their own health risks due to stress [26, 43-45]. Research provides examples of risk factors for next of kin burden for patients with

chronical illnesses, such as female sex, low education, living in the same household, hours spent on caregiving, depression, isolation, financial stress, and lack of choice in becoming a caregiver [46]. People with cancer, younger next of kin, solid tumours, assistance of patient in daily activities are risk factors associated with high caregiver burden [47]. Other studies found a strong correlation between next of kin's self-rated poor health and how the patient perceived the quality of care [48, 49]. For this reason, previous research stresses that healthcare professionals should be better informed about next of kin burden and make a stronger effort to enhance their quality of life. Such an awareness could also benefit and enhance the patient's quality of life [50, 51]. Suggested interventions could be holistic patient care that includes the next of kin as a dyad, special training in pain management, improved communication skills, and the inclusion of the patient and next of kin in decisions of the care plan [52].

There are many negative consequences for next of kin caregivers (e.g., depression, anxiety, distress, fatigue) [53, 54]. However, studies have also emphasised its positive aspects such as developing a resilient coping strategy, spirituality, and personal growth. These aspects can reduce emotional stress and is described to be a protective factor for next of kin' health, adaptation to a new role, and posttraumatic growth [55, 56].

Research on challenges and potential social and ethical implications for the next of kin suggests additional interventions [24]. However, there is an evidence-practice gap in the knowledge of how to translate research findings with applicable methods and tools that are useful for patients, next of kin, and healthcare services [42].

2.4 Next of kin satisfaction with care in relation to quality of care

Next of kin satisfaction with care is highlighted as a critical indicator of quality for patients with advanced cancer, but their satisfaction is only

rarely assessed in healthcare services [57]. Some knowledge exists about next of kin satisfaction with care in Norway and globally [58-66]. One study from 2011 found that next of kin reported good satisfaction in general with hospital cancer care [60]. However, they also found that the most negative dimension of quality of life for next of kin was family concern. Other factors affecting satisfaction with care and quality of life were age, co-residence, relationship to patient, gender of patient and the next of kin, stages of the disease, and marital status [60]. Another study found substantial dissatisfaction among next of kin of patients with advanced cancer in Greenland [59]. In studies of satisfaction with both patient and next of kin satisfaction, patients in general claimed to be more satisfied with care than their next of kin were, especially with coordination of care and family involvement in treatment and care decisions [67].

Research indicates that high satisfaction among next of kin improves patient care [68, 69]. There is, however, an unexplored potential for looking into next of kin satisfaction with care combined with mapping their suggested involvement interest [54, 60] and quality of care.

2.5 Next of kin involvement and perspectives on safety

The relation between next of kin involvement and safety is an underexplored field in hospital cancer care. Paying attention to next of kin experiences and their reports of safety can possible give healthcare systems an early warning when the risk increases [70]. Safety in this field is however not well understood and can have many pitfalls: physical (e.g., medications, infections, environmental hazards); emotional (e.g., strain, caregiver burden); social (community, network); and functional dimensions (health risk for the next of kin, comorbidity, fall prevention) [71]. Research shows that patients with cancer experience more adverse events than other hospitalised groups [19, 39]. With hospitals shortening stays for cancer patients, the responsibility for care that requires

knowledge and assistance from both the next of kin and the patient has increased. This often comprises technical skills, knowledge, and rapid adaptations to the patient's condition. Despite next of kin taking on many care tasks, they are rarely included in the patients' specialised team, and systematic involvement is sporadic [24, 69].

Knowledge of the next of kin' and other stakeholders' role and contribution is emerging as an important field for the understanding of safety in complex adaptive organisations such as hospitals [70, 72-74]. For decades the traditional way of investigating safety in healthcare has been to concentrate on accidents and adverse events, often referred to as Safety I [75]. More recently, there has been a call for a Resilient health care [75]. This theory changes the safety perspective and tries to understand safety by exploring opportunities and why things most of the time goes right. This is Safety II [76]. According to the Safety II perspective, it is the people in the system's ability to adapt to everyday activities that make the system work, e.g. by balancing resources when a cancer patient with low blood cell counts spikes a fever.

Little is known about the role of next of kin and how hospital cancer care services collaborate with them [73, 77]. Despite a growing interest in the role of patient and next of kin in Resilient health care and in the dimensions related to anticipation of risk, responding to treatment, information exchange across care levels [73, 74, 78-81] there is still limited knowledge of how and when next of kin can and should be involved [82].

2.6 Summary of research challenges

This chapter shows that there has been a growing attention to next of kin involvement in healthcare in general and in cancer care [48, 79, 83], in a quality and safety perspective related to resilience in healthcare [48, 73, 74], and in research [37, 84]. Few studies include the safety perspective in next of kin involvement in hospital cancer care. The role and

contribution of the next of kin' for quality and safety in cancer care is not well understood and research and practice lacks methods, guides, and tools to ensure sustainable next of kin involvement in cancer care. There is also an unexplored potential for looking into next of kin satisfaction with care combined with mapping their suggested involvement interest to understand more of the complexity related to next of kin involvement. And finally, little is known about the role of next of kin in facilitating and supporting successful outcomes in healthcare. This thesis therefor will examine next of kin involvement in hospital cancer care with a new perspective focusing on their role in quality and safety.

2.7 Aim, objectives and research questions

The aim of the study was to explore the next of kin role for quality and safety in hospital cancer care and to develop a consensus-based guide for next of kin involvement in hospital cancer care. The objectives were:

- to map next of kin involvement and methods used in two hospitals from the managers' and healthcare professionals' perspective,
- to explore next of kin satisfaction with cancer care services and suggestion for next of kin involvement from the next of kin' perspective,
- to synthesise finding and explore topics and elements relevant for a next of kin involvement guide to support quality and safety in hospital cancer care.

The following research questions guided the thesis:

- How are next of kin involved in hospital cancer care? How do managers and healthcare professionals perceive challenges in next of kin involvement in cancer care? (paper I)
- How are next of kin involved in shaping resilience within cancer care in hospitals? (paper II)

- What are the similarities and differences in next of kin satisfaction with cancer care in two Norwegian hospitals? How would next of kin like to be involved in cancer care? (paper III)
- What topics and elements should be included in a next of kin involvement guide to support quality and safety in hospital cancer care? (paper IV)

2.8 Key concepts

Next of kin

This thesis defines next of kin as patient-appointed stakeholders, caregivers' families, or informal caregivers, their representatives, or healthcare professionals having a stake in the patient across the healthcare system. This is consistent with the definition of next of kin in Norway's Patient and User Rights Act (1999) section 1b, and other definitions of next of kin describing them as stakeholders appointed by the patient [85].

The Norwegian legislation does not specify obligations for the next of kin in the provision of care. However, next of kin have gained extended rights in relation to the term "user" in the Norwegian Patient and User Act section 3-1. Involvement is therefore a statutory right for the next of kin, and healthcare services have a duty in involvement and support accordingly. According to the national guideline for next of kin involvement and support in health and care services in Norway [86], it is mandatory for healthcare services such as hospitals to develop systems and systematic routines that facilitate next of kin involvement. They should also collect next of kin experiences through the organisation and utilise the knowledge in improving service quality and safety. In addition, service providers should have competence on involvement, how to support, and provide oversight of local support measures for the next of kin. Service providers should also collaborate to support next of kin through cooperation agreements [86].

Next of kin involvement

Different terms have been used for describing involvement in care. Among these terms are participation[13], patient engagement[69], stakeholder engagement [87], patient and family-centred care [88], or patient and family engagement [89].

The term "involvement" used in the thesis is similar to the term "patient and family engagement" described by Carman and colleagues [89]. However this thesis operationalises and conceptualises the next of kin' perspective and does not include the patient as a dyad, like many others have done [69, 81, 90, 91]. The definition of "next of kin involvement" in this thesis is:

A set of skills and behaviours provided by the next of kin to foster quality and safety actively in relation to hospital cancer care both with individual support actions or in collaboration with the patient or the healthcare team.

Quality and safety

Quality and safety are a commonly used pair in healthcare services. The relationship between the two is often expressed as a part over a wider multidimensional phenomenon [92]. It has been argued that the two must be explored together to obtain and sustain safe and high quality healthcare services [16, 93-96].

This thesis uses the quality definition from Institute of Medicine that includes six conceptual quality dimensions for healthcare systems to achieve. Safety is here seen as one dimension of quality [95]:

1. *Safe – avoiding injuries to patients from the care that is intended to help them.*
2. *Effective – providing service based in scientific knowledge to all who would benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse, respectively).*

3. *Patient-centred – providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guides all clinical decisions.*
4. *Timely – reducing waits and sometimes harmful delays for both those who receive care and those who give care.*
5. *Efficient – avoiding waste, in particular waste of equipment, supplies, ideas and energy.*
6. *Equitable – providing care that does not vary in quality because of personal characteristics, such as gender, ethnicity, geographic location and socio-economic status [95,p.5-6].*

The Norwegian government also bases its definition of quality in line with the Institute of Medicine and sees safety as a subdimension of quality. This is also a common way of describing safety in other contexts [11, 16, 97]. However, the Norwegian government also uses the concept of quality and safety in a pair [98] and this thesis has chosen to do the same. The thesis applies a broad perspective on quality and safety looking at wide spectrum of events that may influence quality and safety for cancer patients. This means it is not looking into one type of medical or diagnostic errors. It views broadly on risk and all types of adverse events in the trajectory as perceived by healthcare professionals, patient, next of kin, and politicians. This is also in line with the well-known definition of patient safety made by Charles Vincent (2006) [92, 99]:

"The avoidance, prevention and amelioration of adverse outcomes and injuries stemming from the process of healthcare"[99p.14.].

2.9 Structure of the thesis

This thesis is article based. The thesis follows a two-part model. **Part I** is a synopsis and consists of seven chapters. ***Chapter 1*** provides a contextual overview of cancer in Norway, the Norwegian healthcare system and trends in organisation of cancer care services. ***Chapter 2*** provides an overview of previous research of next of kin involvement

(role, methods/tools, complexity) and introduces the thesis' aim with additional objectives, research questions, and key concepts. ***Chapter 3*** presents the theoretical perspectives of the thesis. ***Chapter 4*** offers a detailed outline of the methodology and considerations. ***Chapter 5*** summarises the results in papers I-IV and views the results across the three sub-studies. ***Chapter 6*** offers a discussion of the results from chapter 5 in light of previous research and the theoretical backdrop presented in chapter 3. ***Chapter 7*** concludes the thesis with additional implications for practice and suggestions for future research.

Part II consists of four published peer-reviewed research articles in the thesis and relevant appendices.

Paper I

Bergerod, I.J., B. Gilje, G.S. Braut, and S. Wiig, *Next-of-kin involvement in improving hospital cancer care quality and safety - a qualitative cross-case study as basis for theory development.* BMC Health Serv Res, 2018, 18(1): p. 324.

Paper II

Bergerod, I.J., G.S. Braut, and S.Wiig, *Resilience From a Stakeholder Perspective: The Role of Next of Kin in Cancer Care.* J Patient Saf, 2020, 16(3): p. e205-e210.

Paper III

Bergerod, I.J., I. Dalen, G.S. Braut, B. Gilje, and S. Wiig, *Measuring next of kin satisfaction with hospital cancer care: Using a mixed-method approach as basis for improving quality and safety.* J Adv Nurs, 2020, 76(5): p. 1232-1246.

Paper IV

Bergerod, I.J., G.S. Braut, B. Fagerdal, B. Gilje, and S. Wiig, *Developing a Next-of-Kin Involvement Guide in Cancer Care-Results From a Consensus Process.* Cancer Nurs, 2020, Publish Ahead of Print.

3 Theory

There are several theoretical models and frameworks that can guide quality and safety studies in hospitals [100]. This thesis uses two theories that have guided the field of quality and safety: the Organizing for Quality framework [1, 101] and Resilient health care [76, 102, 103].

3.1 Organizing for Quality framework

The Organizing for Quality framework was developed by Bate and colleagues based on international studies of hospitals in Europe and USA. The framework concentrates on processes to improve organisational performance in quality improvement [1].

The study was designed to help healthcare professionals and researchers to understand factors and processes relevant for quality improvement in healthcare organisations. The Organizing for Quality framework originated in organisational studies and theory, and the purpose was to understand how organisational, contextual, and human factors influence each other within and across service levels in hospitals [101]. The "Quality" concept in the framework yields three components: clinical effectiveness, patient safety and patient experience [100].

Bate and colleagues found that healthcare organisations that were able to achieve and sustain high quality care were successful in resolving six common challenges[1, 101]:

1. ***Structural*** *– the whole challenge around structuring, planning and co-ordinating quality improvement efforts*
2. ***Political*** *– the challenge of addressing the politics and negotiating the buy-in, conflict and relationship of change surrounding and quality improvement effort*
3. ***Cultural*** *– the challenge of giving `quality` a shared, collective meaning, value and significance within the organization*

4. ***Educational*** *– the challenge of creating and nurturing a learning process that supports continuous improvement*
5. ***Emotional*** *– the challenge of inspiring, energizing, and mobilizing people for the quality improvement effort*
6. ***Physical and technological*** *– the challenge of designing physical systems and technological infrastructures that support improvement and quality of care. [1p.169.]*

The most important feature of this framework is, however, not only the six challenges, but also inner context (structure, size, and performance) and outer context (social, political, and technological environment) and how these influence each other. This makes the Organizing for Quality framework stand out in terms of how quality has been studied previously by providing a much more integrated framework [104]. Figure 1 depicts the relationship between the six common challenges and inner and outer context [101].

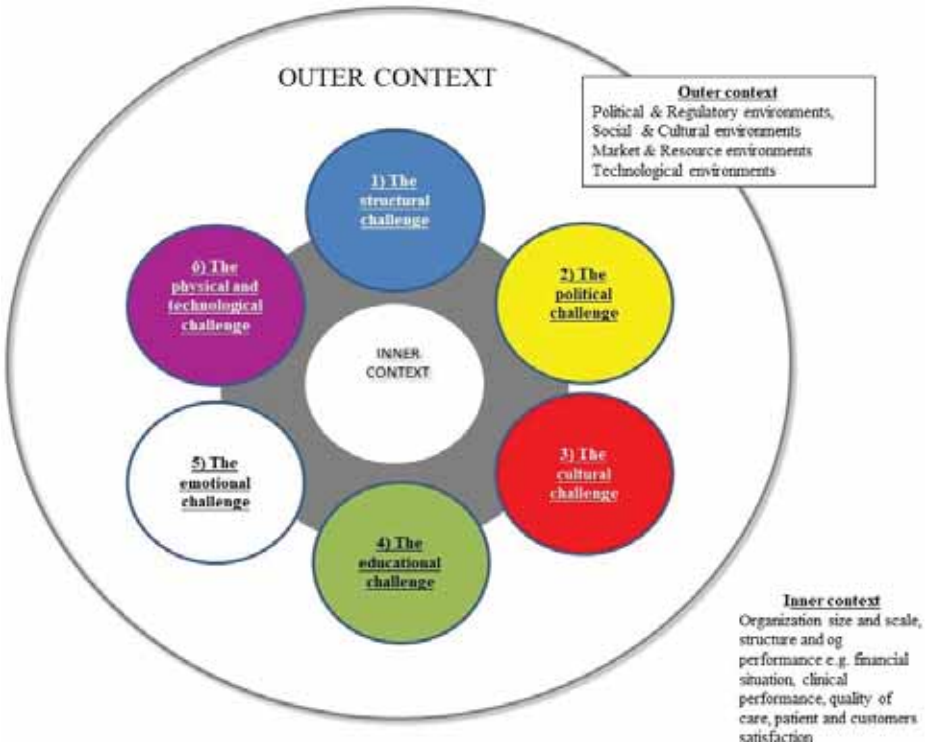


Figure 1 Organizing for Quality framework inspired by Bate and colleagues [101p.3.]

Bate and colleagues present a codebook and a checklist for each challenge. They argue that healthcare professionals and researchers could use the materials to identify quality improvement gaps in their organisation. The colors in the framework are a graphical visualisation of sub-processes of the codebook for each challenge [1].

The Organizing for Quality framework has been applied, tested and refined in several studies in European hospitals [94, 105], and in Norway with successful adaptations [106-108]. This shows that the Organizing for Quality framework is widely applicable, but the framework should also be further tested and developed in terms of stakeholder involvement [108].

The Organizing for Quality framework has been the theoretical backdrop of the thesis and has guided all three sub-studies. It was the foundation for the interview guides for the micro level (healthcare professionals) and meso level (managers), it was used to analyse the data material for sub-study I, and it was a fundamental in structure for the consensus-based guide for involvement of next of kin in cancer care services.

There are several reasons for choosing the Organizing for Quality framework as the theoretical perspective in the thesis. First, the framework focuses on system thinking (how and why things work or not) and is designed to allow for identification of gaps that need to be addressed to improve quality. Second, the Organizing for Quality framework propounds that quality is a multilevel- phenomenon and a social process [1].

…we see quality as not just a method, technique, discipline or skill, but as a human and organizational accomplishment, something that is constructed by people in their everyday actions and interactions with and for each other – a social process [1p.8.].

This is relevant for understanding next of kin involvement as a phenomenon, not only as a contribution to quality improvement processes, but something happening among stakeholders within the hospital cancer care setting. Moreover, the framework was tailored for the hospital context. And finally the framework's multilevel perspective by considering the inner and outer contexts was relevant and helpful to understand quality and safety processes in cancer care in the study [1].

3.2 The Resilient health care theory

3.2.1 Safety I and II

Safety in the healthcare service has moved from focusing on the individual's role and responsibility for safety, to a system perspective

[109]. Traditionally, when promoting safety in healthcare, the focus has been to understand "what went wrong" to prevent it from happening again. In the literature this is often referred to as **Safety-I**: *"A condition where the number of unacceptable outcomes (accidents/incidents/near misses) is as low as possible"[76p.126.]*. This perspective focuses on the detection and management of adverse events. However, adverse events still happen in healthcare services despite decades of trying to provide safer care for patients [19, 110]. The Safety-I perspective centres on how work should be done and has been criticised for not requiring a deeper understanding of healthcare professionals' work and how they adjust to patient conditions in everyday clinical work [102].

To understand safety in healthcare services, the complexity of the system and why it usually provides safe services needs more attention [111]. This perspective is called **Safety II**: *"A condition where the number of acceptable outcomes (meaning everyday work) is as high as possible"[76p.126.]*. The Safety II perspective is, according to Hollnagel, more proactive and unlike Safety I. It concentrates on what "goes right" in healthcare organisations with high degree of variability and adaptations in everyday performance [76, 111]. An example of such variability in the hospital cancer care setting could be more patients admitted to the ward than expected, lack of medication, use of technology or a patient's sudden deterioration resulting in a need for changes in work tasks and personnel, or involvement of patient and stakeholders. The key message of a Safety-II perspective is to find out what these adjustments and variations are and learn from why they succeeded, in addition to learning from the adverse event (Safety-I) [111].

3.2.2 Resilient health care

As part of the Safety II tradition, the interest in Resilient health care has grown since 2012. The theory is slowly starting to influence the

understanding of safety in the healthcare services and has become an established research field [103].

The Resilient health care theory is adapted from other research traditions and there exits many definitions of the concept [112]. Most known is resilience engineering that relies on a definition that a system is considered to be resilient if it can adjust its functioning before, during, or after an event that disturbs its state [113-115]. The theory has been applied to aviation, nuclear power plants, oil industries, and natural disasters [116].

A premise of Resilient health care theory is that healthcare services such as hospitals are *complex adaptive systems* (CAS) meaning large, non-linear organisations with high degrees of variability and adaptations in everyday performance [72, 117]. In complex adaptive systems, it is argued that it is the people that adapt and perform that constitutes the system [117, 118]. Relationships are therefore described as keys in the understanding of complex adaptive systems [119]. This could be seen as a contradiction to the Safety I perspective that uses a more rigorous and linear descriptions of a system. Safety I is criticised for failing to recognise the dynamics and complexity in healthcare organisations with inherent actors (managers, patient, next of kin, healthcare professionals) and uncertainties with emerging changes or disruptions (economy, resources, culture, patient condition) in everyday clinical practice [72, 118]. Resilient health care has been defined in different ways [77, 115, 120]. This thesis has applied the Resilient health care definition proposed by Hollnagel and colleagues [76]:

Resilience is an expression how people, alone or together, cope with everyday situations – large and small – by adjusting their performance to the conditions. An organisations' performance is resilient if it can function as required under expected and unexpected conditions alike (changes/disturbances/opportunities)[76p.14.].

Resilient health care has a system perspective that incorporates adjustments done before and after change. In addition, the theory emphases everyday micro-level clinical work in terms of positive effects, opportunities, and successful outcomes [76]. Resilient health care is closely connected to quality of care, and how adaptations reduce risk and lead to safe work practice and successful outcomes. However the literature also notes that adaptations can have negative outcomes [77, 121]. Wiig and colleagues [77] have refined the definition of healthcare resilience to *"The capacity to adapt to challenges and changes at different system levels, to maintain high quality care."* This definition shows a strong connection to quality of care. The focus on quality makes the Resilient health care theory even more relevant to this thesis. This refined definition of resilience also has a system perspective, but provides more insight into resilience in healthcare as a multi-level phenomenon which is argued to be more applicable to research in the field of healthcare [77].

This thesis argues that the different definitions of Resilient health care [82] have the same fundamental assumptions of resilience as a multi-level phenomenon, although they differ in the concepts used for understanding everyday practice.

3.2.3 Key concepts in Resilient health care

There have been several attempts to use and define key concepts for healthcare systems'resilience [122]. Hollnagel and colleagues suggested Resilient health care operationalised into the four basic potentials for resilient performance [76] :

1) *The potential to **respond.** Knowing what to do or being able to respond to regular and irregular changes, disturbances and opportunities by activating or creating new ways of doing things*

2) *The potential to **monitor**. Knowing what to look for or being able to monitor that which affects or could affect an organization's performance in the near term – positively or negatively.*
3) *The potential to **learn.** Knowing what has happened or being able to learn from experiences, in particular to learn the right lessons from the right experiences.*
4) *The potential to **anticipate.** Knowing what to expect or being able to anticipate developments further into the future, such as potential disruptions, novel demands or constrains, new opportunities or changing operating conditions [76p.26-27.].*

The four potentials constitute a set of functions that all need to be present in organisations to enable resilient performance [76]. The potentials are interconnected, and it is argued that all of them are necessary and essential for understanding human and organisational performance in healthcare [76].

Anderson and colleagues suggested in 2016 the Concepts for Applying Resilience Engineering (CARE) model as a framework for exploring organisational resilience in healthcare systems and how it contributes to successful or unsuccessful outcomes [123]. The CARE model emphasises a need for alignment between demand and capacity in healthcare (Work as Imagined) through understanding adaptation and adjustments done in healthcare practice (Work as Done) and how it contributes to successful or unsuccessful outcomes of healthcare [123].

Lately, Berg and colleagues argues that resilience characteristics are the same across system levels (micro, meso, macro) and suggest common resilience characteristics operationalised as anticipation, sensemaking, trade-offs and adaptations as key concepts for resilient health care [124, 125]. Alignment between government expectations and guidelines, and compliance from managers and healthcare professionals in clinical practice is a challenge that is prominent in the healthcare system in Norway [98, 126, 127]. It is argued for developing methods and tools

that could bring the levels closer together, and the latter key concepts are therefore relevant for this thesis.

Recently, Anderson and colleagues have presented an Integrated Resilience Attributes Framework [77] that emphasises adaptive capacity [128]. This framework is relevant for this thesis because it so strongly articulates and includes a broad stakeholder perspective with the patient and next of kin as valuable sources of resilience in healthcare systems [77, 128].

Nevertheless, despite several efforts of defining key concepts in resilience in healthcare, it is still argued that the field lacks conceptual clarity [122]. Resilient health care theory has also been criticised for the lack of empirical testing [113, 116, 124, 129]. Moreover, the literature on resilience in healthcare lacks descriptions of next of kin and stakeholder perspectives [73]. A recent review of Resilient health care studies [124] confirms the lack of studies of resilience as a multi-stakeholder phenomenon. There is also an unexplored stakeholder role in Resilient health care. Even if O'Hara and colleagues [73] are speaking of how families scaffold the healthcare system, and Wiig and colleagues [79, 80] talk about how next of kin want to be involved and have in-depth knowledge about the patient, the service provided and the system, the stakeholder perspective and the role of next of kin are underexplored in the resilience literature [74, 75, 130].

In this thesis, the four basic potentials for resilient performance have been used as an analytical tool with the potentials as predefined categories. The rationale for choosing the potentials was to utilise key concepts in Resilient health care theory that up until today has had the largest impact of the Resilient health care research field [82]. The goal has been to explore and test the framework with a stakeholder perspective in the cancer care context. Using the potentials has contributed to an in-depth understanding of the next of kin role and what

they contribute to in the hospital cancer care context to support resilience in health care.

3.3 Rationale for choice of theory in the thesis

The rationale for the choice of the two theoretical frameworks is closely connected to their similarities in terms of understanding work processes in healthcare that ensure quality and safety in cancer care.

The Organizing for Quality framework seeks successful processes and for healthcare services to respond to common challenges in the organisations. Through descriptions of how the healthcare system handles these challenges, the goal is to understand quality and safety in healthcare.

Resilient health care theory also looks for successful outcomes but is limited to studying variations and adaptations by managers and healthcare professionals dealing with stress, changes, and lack of resources to ensure quality and safety.

This thesis uses both theoretical perspectives to understand predefined challenges and potentials related to how stakeholders in the meso and micro level of hospitals cancer care service solve them, and in addition how next of kin involvement is key in the process of creating service quality and safety. The two theories complete each other by bringing in significant constructs of the macro, meso and microlevel connection and the importance of context, that the hospitals operate within.

Based on these foundations and study findings, theory development has been suggested for research, and a guide for involvement of next of kin in hospitals' cancer care has been developed.

4 Methodology

This chapter summarises the mixed methods research conducted in this thesis. The chapter starts with a presentation of the philosophical underpinnings of mixed methods research and continues with a presentation of the design of the thesis' three sub-studies. It consists of a detailed description on study design, cases, recruitment process, study participants, and the analysis process. It also provides details of methodological considerations, research ethics, trustworthiness and ends with a reflection on the researcher's role in embedded research.

4.1 Philosophical underpinnings of mixed methods research

A paradigm reflects the researcher's worldviews and assumptions accompanied by methodologies and methods [131, 132]. Quantitative methodologies often apply the positivistic paradigm focusing on laws of nature, measuring, observations, and experimental designs [133]. A qualitative methodology often applies the constructivist paradigm with an inductive, holistic and subjective focus where interpretation, context and phenomenon are closely connected [133]. Some researchers argue that the mixing of these two research traditions is an attempt to combine two incompatible paradigms [134, 135]. In line with the mixed methods research tradition, this thesis uses pragmatism as the underlying worldview [136]. Pragmatism posits that all knowledge comes from experience, and that all human action is based on past experiences and what the individuals have learned [137]. The philosophical stance of pragmatism accepts that there is a reality without human existence, but that it can only be encountered through human experiences [137].

The core assumption of pragmatism is however that research questions are leading more than philosophical underpinnings of the paradigms [138]. In other words, the researcher has taken a pragmatic perspective

to the incompatible discussions and comprised elements of qualitative and quantitative research traditions in light of the aim and research questions in order to justify and strengthen the mixed methods design [133]. Mixed methods research is in this stance not a “third paradigm” but a theoretical method that involves connection and integration of qualitative and quantitative research traditions [138].

For this thesis, both methodologies were needed to understand how next of kin involvement as a phenomenon and experiences were understood from the perspectives of next of kin, healthcare professionals, and hospital managers. By combining methods from both methodologies, with respective limitations and strengths of both related to paradigm perspective, epistemology and philosophical orientation, the goal was to answer the research questions in the best way to justify and validate the results of the study.

4.2 The mixed methods thesis

4.2.1 Study design

This thesis applies a mixed methods research design. Mixed methods research combine and integrate quantitative and qualitative data with the goal of providing a stronger collective understanding [139, 140]. This research design has been widely used in health and social sciences to investigate complex phenomena [141]. The mixed methods design and the different methods in this thesis was chosen to investigate the research questions that by nature are connected to the two methodologies.

More specifically, this thesis has used a mixed methods case study design involving the mixed methods convergent design as a core Fig. 2., inspired by Creswell and colleagues [139p.231.]. The convergent design in this thesis means that qualitative and quantitative data have been collected and analysed separately in parallel, before the mixing methods integration.

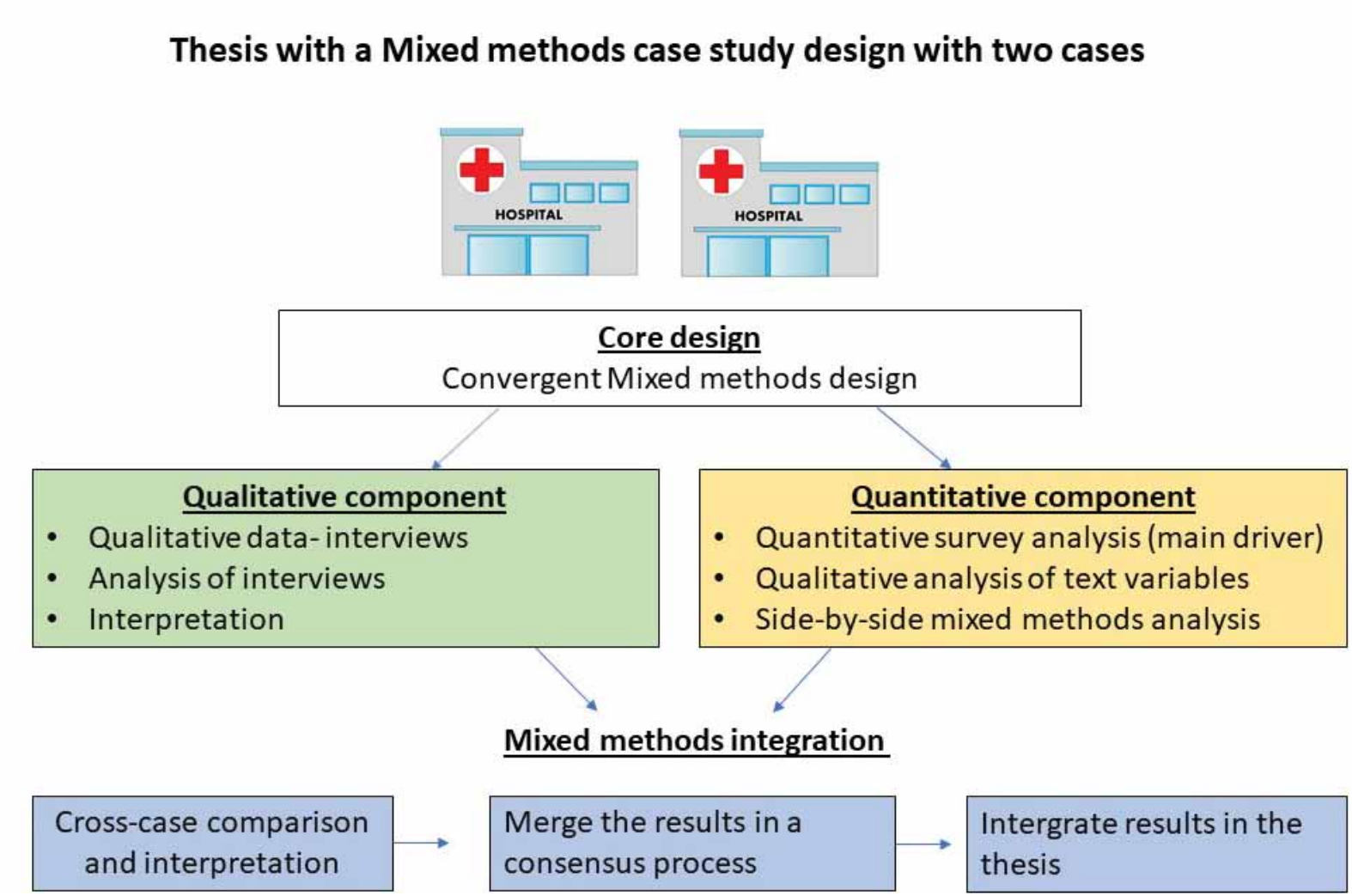


Figure 2. Overview of the thesis mixed methods case study design with two cases

The thesis consists of triangulation of methodologies, methods and units of analysis [142]. All of them leads to answer the research questions of the thesis [136]. Qualitative and quantitative data have been collected and analysed separately. There are many ways of integrating data in a mixed methods study [140, 143, 144]. The mixed methods results have been merged and integrated to reinforce the understanding of the two methodologies, answering the research questions and creating a deeper understanding of next of kin involvement in hospital cancer care.

Figure 3. depicts the design of the three sub-studies in this thesis (See also Figure 2:

- Sub-study I: Semi-structured interviews with managers and healthcare staff (n=32)
- Sub-study II: A questionnaire survey with next of kin (N=238) supported with qualitative open-ended questions
- Sub-study III: A consensus method process based on a modified Nominal group technique with 20 stakeholder participants.

The sub-studies will be presented later in this chapter (See chapter 4.3).

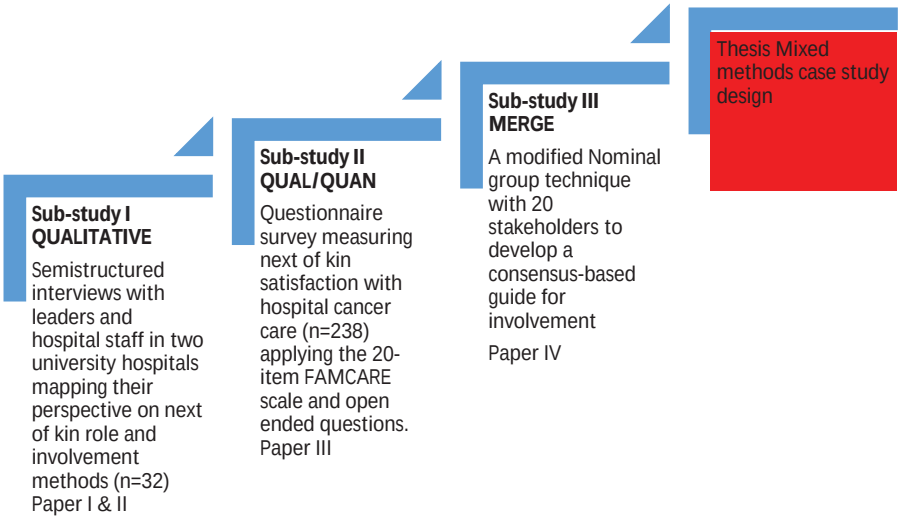


Figure 3. Overview of the mixed methods case study design with sub-studies inspired by [140].

The sum of the results from all the three sub-studies constitutes the mix-methods dissertation (Figure 3). This is in line with the mixed methods case study design by Creswell (2018) [140]. The case study is chosen as a research strategy because "next of kin involvement in hospital cancer care" cannot be explored without its context. For the thesis, a case is defined as one hospital with its cancer department. Two cases were included.

4.2.2 Case selection and study setting

Two cancer care departments at two Norwegian university hospitals constitute the cases in this thesis. The hospitals were selected by approaching the head of the cancer care departments in both hospitals with discussions and presentation of the project plan. The hospitals are both university hospitals in the same Regional Health Authority (RHA) in Norway. The hospitals are different in size, budget, and organisations, but share the same obligations to national and regional policy documents which make them comparable. The cancer care departments have

different organisational structures. Table 2. provides an overview of key figures for the case hospitals. The cancer care department at Hospital A consists of two in-patient cancer care wards, two out-patient clinics and one radiotherapy unit. Hospital A is the second-largest hospital in the RHA. The cancer care department in Hospital B consists of two in-patient wards, one out-patient ward and one radiotherapy unit. This hospital is the main regional cancer care department in the RHA.

Local context	Large city in Norway	Large city in Norway
Included hospitals	Hospital A	Hospital B
Size	University hospital Local hospital for 330.000 inhabitants	University hospital Local hospital for 420.000 inhabitants
Employees	7500	12.000
Budget	6,8 billion NOK	10.8 billion NOK
Departments	Second largest regional cancer department	Main cancer department in the region

Table 2. Key figures of the case hospitals

4.3 Presentation of the sub-studies

4.3.1 Sub-study I

The aim of sub-study I was to explore the influence of next of kin involvement on quality and safety in hospital cancer care. This study was also a qualitative mapping of next of kin involvement and involvement tools and methods used in hospital cancer care. Sub-study I resulted in two published articles [145, 146].

Sub-study I was a comparative multiple embedded case study of cancer departments in the two hospitals. Embedded in this setting is understood as including micro, meso, and macro levels of several service [147]. The

comparative design identifies similarities and differences between the two cases hospitals.

Data collection

Sub-study I triangulates several data sources at the micro, meso, and macro service levels. The **macro level,** national (e.g. regulations, reports to the parliament) and regional and local policy documents were read to explore the macro level context with focus on next of kin involvement in general [9, 148], in cancer care [149], and in quality and safety [150]. The purpose was also to understand more of the context that managers and healthcare professionals were affected of in their daily work. At the **meso and micro levels,** qualitative semi-structured interviews with 13 managers and 19 healthcare professionals from the two hospitals were conducted from December 2015 to March 2016.

Recruitment and participants

The informants were recruited by their nearest manager with the support of a local coordinator in both hospitals (project manager was the coordinator in hospital A). The coordinators were appointed to ensure that all managers who recruited informants, and the informants themselves, received all necessary information of the study, methods, limitations, their role and the possible outcome of the research. The coordinators and the managers created a schedule based on the plans of the informants and the resource needs of the ward. Table 3 provides an overview og the participants in sub-study I.

The selection criteria for this sub-study were based on a desired variation in the sample, for informants with different positions, age, service levels and experience. The criteria served as a guide for the managers' collaboration and discussions with the local coordinators. Snowball sampling was also used. This strategy was useful if there were difficulties in the recruitment process, or to identify informants who had a special interest and competence in the topic [133].

	Hospital A	Hospital B
Consultant	3	4
Nurse	6	2
Oncology nurse	6	6
Quality manager	1	-
Meso level (managers)	7	6
Micro level (staff)	9	10
Total	**16**	**16**

Table 3. Overview of participants sub-study I

The interviews

The interviews took place in a neutral room in both hospitals. At the start of the interview the researcher ensured that the informant had understood that it was voluntary to participate and gave the informant the opportunity to withdraw from the study. This was stressed to avoid any ethical considerations due to the managers' role in the recruitment process. All informants signed informed consent. The interviews followed a guide developed with themes from the theoretical framework Organizing for Quality framework [1] with additional questions related to the service level of the participant. Interview guides for the micro and meso level are available in Appendix 5 and 6. The semi-structured interview form allowed informants to share their view and story more freely, and for the researcher to examine interesting and surprising themes or questions that arose during the session [133]. Nearly all interviews were conducted by the author of this thesis. Three interviews were conducted by another researcher to ensure validity (chapter 4.5. Research Ethics). The interviews were tape recorded and transcribed.

Data analysis

Data was analysed by using content analysis. Content analysis is a flexible method of analysing, organising and deciphering large amounts of data, like transcribed interview texts in order to develop and extend knowledge [133, 140].

The content analysis in sub-study I was done in inductive and deductive stages [151, 152]. The inductive stage was done first and was appropriate to embed because of the limited knowledge of next of kin involvement related to quality and safety in the literature. The inductive approach is a search for patterns where the researcher seeks similarities and differences with various levels of abstraction and interpretations [153]. The inductive approach followed a three-step process:

1) Selection of hospitals and departments (cases) and units of analysis (informants and interviews)
2) Open coding directly from the transcribed interviews (plain text) and defining categories and sub-categories for each of the cases and service levels within each case
3) a cross-case comparison of the two hospitals and service levels to seek for similarities and differences

The second phase was deductive analysis. The deductive approach is theory-driven [153]. A directed content analysis was inspired by Hsieh and Shannon [154]. The main reason for the choice of analysis method was to use a method that could build upon the empirical testing of the Organizing for Quality framework, and to determine the relationship among the six challenges in the theoretical framework and our research questions [1, 154]. For this analysis the transcribed interview material was categorised according to predefined codes using the six challenges in the Organizing for Quality framework [1]. These analyses followed a three-step process:

1) Selection of hospitals and departments (cases) and units of analysis (informants and interviews)
2) Organising data with predefined categories, selecting meaning units, condensing text, and defining sub-categories
3) And finally, across-case and across service levels description of findings within the six predefined categories

All members of the research team participated in the inductive and deductive analysis process using a group consensus approach inspired by Krein and colleagues [155] to strengthen the validity of the results. The team read the interviews individually and met three times to reflect and discuss the analyses. In addition, several iterations were done by the author of the thesis with all co-authors.

Paper II [146] was inspired by the inductive analysis in paper I. The next of kin role linked to Resilient health care emerged from the analysis, and to explore the link a directed content analysis was conducted, guided by the four resilience potentials [76, 102]. The analysis followed the same stages as the deductive approach in paper I. The author of the thesis led the analysis with meetings and close discussions with all co-authors in paper II.

4.3.2 Sub-study II

Sub-study II applied a convergent parallel mixed methods design with a questionnaire variant [140, 156].

The aim of the study was to measure next of kin satisfaction in hospital cancer care with the use of the 20-item FAMCARE scale survey instrument, combined with mapping their suggestions for involvement methods to improve quality and safety. A qualitative content analysis was performed based on the embedded open-ended questions: *Based on your experience, how should involvement of next of kin be done to improve quality and safety in cancer care? Do you have any specific suggestions?*

There were two reasons for using a mixed methods design: 1) the need to expend the understanding of the quantitative results of how satisfied next of kin are with more information on suggested involvement methods or tools, and 2) understand more of the role next of kin hold in relation to quality and safety. Both reasons create a solid basis for answering the

research questions in this sub-study, and for the use of the result as a basis for sub-study III.

The Questionnaire Survey

The 20-item FAMCARE Scale was used to assess next of kin satisfaction with care. The scale is a well-known instrument used to measure family satisfaction with advanced cancer care [62-64]. The reason for using the FAMCARE instrument was the need for a validated instrument used in the Norwegian cancer care context that covered items relevant for next of kin involvement in cancer care (e.g., information, care service, availability of healthcare professionals). Permission was obtained to use the Norwegian version of the survey (Appendix 7). This version was translated and validated by Ringdal and colleagues [62, 63]. The translated version is presented in Appendix 10.

The questionnaire survey was conducted in three parts. First, next of kin were asked to give information to map their age, gender, relationship with the patient, children living at home, education and length of employment. We also asked them to disclose variables of the patient's age, gender, diagnoses and length of contact with the cancer department.

In the second part they were asked to respond to the FAMCARE survey's 20 aspects of cancer care along a 5-point Likert scale. In the third part of the questionnaire we invited the informants to answer the open-ended questions.

Sample/participants and inclusion

A consecutive sampling strategy was used for this sub-study [133]. All next of kin to patients with a cancer diagnoses in the seven in-patient and out-patients wards in the respective cancer departments, that met the inclusion criteria in this study, were invited to the survey. Inclusion criteria of this study were:

- Been in contact with the hospitals 3-6 months
- Be over the age of 18

- Be able to give informed consent
- Be able to read and write Norwegian
- Appointed by the patient.

Data collection and recruitment

Selected healthcare professionals at seven in-patient and out-patient wards at the two cancer care departments invited patients to participate in the study. If patient consent was approved, the healthcare professionals approached the patient's next of kin and invited them to participate in the survey. The healthcare professionals in charge of the recruitment were given information and informal training in how to administer the questionnaire, and the researcher's contact information if there were unforeseen challenges from the patient, next of kin or healthcare professionals. Between November 2016 and November 2017, 250 patients and their next of kin were contacted in each hospital. A total of 238 next of kin from both hospitals responded.

Data analysis

Quantitative data analysis

Statistical analysis for this study was conducted in IBM SPSS v.24, unless otherwise stated. Missing data on any variable was excluded per analysis. Statistical significance was set at $p \leq .05$. Descriptive statistics with characteristics of sociodemographic and clinical variables were captured to describe the sample, including information on both the next of kin and the patient. Descriptive statistics of individual items' scores for the FAMCARE scale are presented as means and standard deviations (SD). Item responses "Not relevant" were treated as missing. Descriptive statistics were also presented as counts and percentage, in presenting next of kin responses "satisfied" and "very satisfied" for each hospital. These were compared using Poisson regression model with robust standard error, for direct estimation of relative risks/probabilities (RR) [157]. Both unadjusted and adjusted RR were reported with 95% confidence intervals (CI) and p-values from Wald test. An exploratory

factor analysis was performed in R v.3.4.1 with package psych [158], to explore and cluster the variables in the FAMCARE scale by looking at relationships among the 20 items. The FAMCARE items are ordinal, and standard factor analysis is based on Pearson correlation which may not be appropriate. For this reason, we applied factor analysis based on polychoric correlations, which assumes that the responses are the results of a discretising of an underlying continuous distribution [159]. Missing data was excluded pairwise.

Parallel analysis was used to decide on the number of factors in this study [160], where size of eigenvalues was compared with eigenvalues obtained from random samples of equal size as the sample (equal number of subjects and equal number of variables). We kept the factors with eigenvalues larger than the mean of corresponding eigenvalues from the resampled data. This method of deciding the number of factors is more accurate than and preferable to Kaiser's criterion and the Scree test [159, 161]. We tried various extraction methods, which gave consistent results. The results presented were from using maximum likelihood extraction, and after application of direct Oblimin oblique (non-orthogonal) rotation. Item 14 was taken out of the analysis in line with Ringdal and colleagues' [62, 63] suggestion.

Further, we explored the data after grouping items loading ≥ 0.6 on a factor. With the use of linear regression, we compared these group means and means of satisfaction with care scores in the total FAMCARE scale (with and without item 14) between hospitals and between groups of respondents. Due to skewness in these group/total scores, descriptive statistics were presented as median and interquartile range (IQR), and the mean scores were log-transformed prior to the regression analysis. Regression coefficients were exponentiated, forming effect estimates interpretable as percent difference in median scores [162]. Wilcoxon Signed Rank Test was used to compare groups/hospitals.

Qualitative data analysis

One hundred of the 238 participants in the survey answered the embedded open-ended question. The data material was rich, and we used content analysis to make sense of the responses with a four-step interpretive analysis process inspired by Graneheim and colleagues [153, 163]. This qualitative content analysis made it possible to analyse both manifest and latent content [163]. The four steps process were:

1) Discover meaning units in plain text

2) Condensing meaning units with descriptions close to text, and with interpretations

3) Open coding leading into sub-categories and categories with description on the manifest content

4) Comparison across hospitals to rebuild emerging themes on the latent level.

The interpretive process was led by the thesis author with several iterations with members of the research team.

Side-by-side mixed methods analysis

The quantitative and the qualitative analysis were done separately in parallel and merged in a side-by-side comparison in the discussion section in paper III [164]. This is a common way of doing mixed methods analysis and is suggested by Creswell and colleagues [156]. The quantitative component was the main driver in this sub-study; however, both components were integrated and supplemented each other to strengthen the understanding [156]. The analysis consisted of comparing the results of quantitative and qualitative analysis and describing convergence, similarities, differences, or new dimensions from the results.

4.3.3 Sub-study III

Sub-study III used a consensus method process based on the Nominal group technique process where findings in sub-studies I and II were merged, synthesised, and presented for an invited stakeholder group. The aim of this study was to develop a next of kin involvement guide for use in hospitals. Its main purpose was to increase focus on next of kin involvement and to use their experiences to improve quality and safety in hospital cancer care. The research question for this sub-study was: *"What topics and elements should be included in a next of kin involvement guide to support quality and safety in hospital cancer care?"*

Three questions guided the consensus process with the stakeholders:

a) *What can we learn from next of kin experiences with hospital cancer care?*
b) *How can next of kin experiences be valued more systematically to improve the quality and safety of cancer care?*
c) *What methods or tools are appropriate for collecting experiences and for next of kin involvement locally, regionally, and nationally?*

Study design and setting

The study design for this sub-study was a consensus process inspired by the Nominal group technique [165, 166]. This sub-study represents the merge by means of integrating results from sub-studies I and II in the consensus process. In this sub-study the results were presented to 20 invited stakeholders (managers and healthcare professionals from the same two hospitals that constitute the case study setting, next of kin representatives and next of kin stakeholders) (See table 4).

Participant and recruitment

Purposive sampling was used to identify all stakeholders [133]. Participation of healthcare professionals was voluntary and done in close

collaboration with department managers at both hospitals. The managers recruited the participants from two service levels (managers and healthcare professionals) from the seven in- and out-patient wards in the cancer departments. The next of kin representatives were identified by contacting a coping centre in both hospital cities. The centres were willing to participate in the consensus process, and with the use of snowball sampling the centres identified a local next of kin that were able to participate. In line with the Regional Health Authority guidelines a regional next of kin representative was appointed by the Regional Health Authority. Twenty participants accepted the invitation to attend a one-day meeting (See Table 4).

Participants	Attendees
Local next of kin representatives	2
Regional next of kin representatives	1
Coping centre next of kin representatives	2
Physicians	5
Oncology nurses	10
Gender	18 female and 2 males
Service level (meso/micro)	5 managers 15 healthcare professionals

Table 4. Overview of the participants in the consensus meeting

The Nominal group technique process

The Nominal group technique process was developed by Delbecq and Van (1975) [166]. The technique is a consensus method, also known as the expert panel [167]. Consensus methods are often used as a research technique, but are adapted and implemented depending on the research objective [168]. The method is flexible, but is described as a structured process with several stages in a face-to-face meeting: silent generation individually in writing; a round robin process with idea generation presented on flipcharts; clarification through grouping similar suggestions and discussing each idea; and finally individual voting through rating or rank [166, 168].

The meeting took place in the city of one of the case hospitals. The arena had no affiliation with the hospital. Half of the participants had to travel by plane to attend the meeting. The author of the thesis had received funding from Nora Smedvig Foundation to cover the participants' travel expenses, refreshments, and meals for the meeting.

The meeting was organised with a modified three-phase consensus process (Figure 4.) [166].

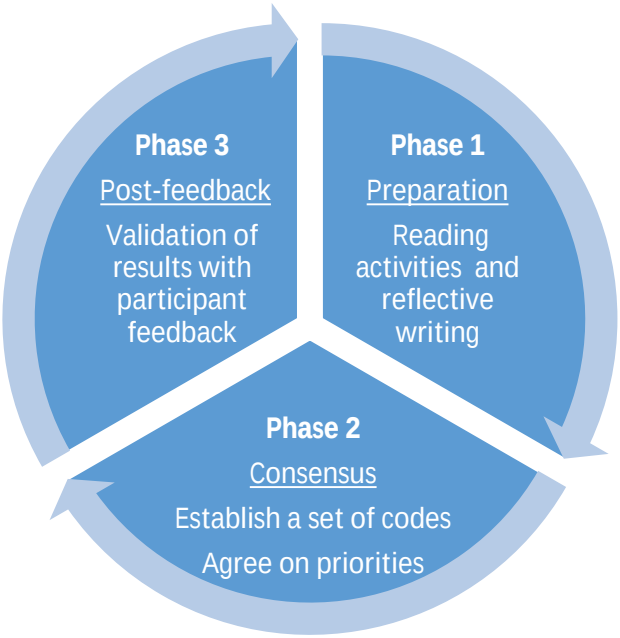


Figure 4. The three-phase consensus process for sub-study III (From paper IV [169]).

Phase 1 was done by email. One month ahead of the meeting, all participants received published articles from sub-study I which described the PhD project. The participants were asked to read the articles and reflect on the topic of the meeting. We also requested that they answered the three questions that would guide the meeting (presented above). We wanted to empower the participants by helping them to prepare for a discussion on the topic and to begin their reflection before they met the

other participants. The participants sent in a one-page answer to the thesis author who conducted a qualitative content analysis inspired by Graneheim and colleagues [163] with focus on the manifest content, leading into sub-categories and categories. The analysis was presented and used as an "icebreaker" in the beginning of the meeting in phase 2. In **Phase 2** the face-to-face meeting took place. Its purpose was to reach consensus on the top five priorities for next of kin involvement in hospital cancer care. This phase had two parts: a) to establish a set of codes through a group consensus approach; and b) to agree on top priorities by individual voting. **Phase 3** was completed one week after the face-to-face meeting. The participants received an email with the results and an invitation to comment. One comment was received from the participants and was noted.

Mixed analysis – the next of kin involvement guide

When developing the next of kin involvement guide presented in paper IV [169] we applied an earlier modification of the Organizing for Quality framework for the cancer care setting (Model 1) [145], and integrated the results from the consensus process. The intention was to give the modified Organizing for Quality framework for the cancer care setting a broader empirical foundation with practical usability. The top priorities from the stakeholder groups corresponded well with the modified Organizing for Quality framework. We grouped all codes (not just the top five) according to the six challenges in the framework. We integrated all priorities suggested by the stakeholder group for two reasons. First, the stakeholders did not state that the additional codes were not important. Second, when embedding the additional codes, the six quality challenges became a stronger and more helpful practical guidance tool for translating theory into practice in hospital cancer care.

4.4 Methodological considerations

Trustworthiness in mixed methods research

There is an ongoing debate what quality criteria should be associated with mixed methods research [170]. Terms like rigour and validity are often associated with the positivistic paradigm (quantitative research) and it is argued that these terms do not fit the constructive or interpretive paradigm [133]. There are different quality criteria that can be assessed in a mixed methods study [134, 135, 171, 172]. However, there is no consensus in mixed methods literature on quality criteria that fits every study. This thesis uses "The quality framework" by Tashakkori and Teddlie (2008)[173] which is further operationalised by O'Cathain (2010) [174]. This framework consists of eight domains that need to be addressed in mixed methods research to assess its quality (1. Planning quality, 2. Design quality 3. Data quality, 4. Interpretive rigour, 5. Inference transferability, 6. Reporting quality, 7. Synthesizability, 8. Utility). The eight domains are clustered in five stages of a research project: Planning, undertaking, interpreting, dissemination, and application in the real-world stage. The domains and how this thesis addressed them will be presented in the five stages below, starting with the planning stage.

4.4.1 Planning stage

Domain 1: Planning quality

This domain describes how the study has been planned. The domain has four items relevant to this thesis: *Foundational element, rationale transparency, planning transparency and feasibility [174].*

The thesis meets this domain by embedding the Organizing for Quality framework [1] as the *fundamental element* and the conceptual theoretical foundation for the study through all phases. In addition, the aim and the research questions build upon a knowledge gap on the next of kin role in quality, safety and involvement. The latter leads us to the *rationale for*

transparency which is the rationale for justifying a mixed methods approach. The literature presented in the introduction demonstrates the need for mixed methods research in this area. The planned mixed methods study has been *feasible* with regards to the timeline outlined in the PhD proposal of six years with 50 % research time. The project has, however, both been complex and comprehensive, demanding a great deal of organisation and planning for the next stage. One example is the applications for funding so that the consensus meeting with stakeholder participants in sub-study III could proceed as planned.

4.4.2 Undertaking stage

Domain 2: Design quality

This domain is a key component consisting of items concerning the design of the study. Four criteria items are relevant here: *Design transparency, Design suitability, Design strength and Design rigour [174]*.

This study meets the *design transparency* criterion by elaborating on the Mixed Methods Case Study Design described in the "Study design" chapter. In addition, the design includes a convergent design as a core inspired by Creswell (2015) [139]. As a result, the sub-studies with additional papers have used other designs based on methods used in the study to fit the aim and research questions. Sub-study I is a comparative multiple embedded case study, Sub-study II is a convergent parallel mixed methods design with a questionnaire variant, and sub-study III a consensus method process based on the Nominal group technique process. The design quality is especially evident in paper III which is a mixed methods article that describes design transparency.

The design and methods used in this PhD study were *suitable* and corresponded well with the research questions and findings. The *strength* of the study is demonstrated in sub-study II (paper III) where potential weakness in the main (quantitative) driver was supported with open-

ended (qualitative) questions to answer the research questions. This is in line with pragmatism as the philosophical underpinning of this thesis (see 4.1).

Design rigor is ensured by following recommendation for Mixed Methods Case Study Design and Convergent Design suggested by Creswell [140]. The triangulation of methods in the study supports design quality by compensating for potential weakness in one study with strength in another [174].

Domain 3: Data quality

This domain consists of five element items relevant for addressing the quality of the data collection and analysis: *data transparency, data rigor (design fidelity), sampling adequacy, analytic adequacy, analytic integration rigor.*

Data transparency is obtained by in-depth descriptions of data collection, recruitment process, participants, setting and analysis used for each sub-study, and additional information in the methodological chapter. Data is also available on request.

All three sub-studies were carried out as planned. However, data collection in sub-study II (the survey) took longer than expected due to changes in recruitment personnel and patient flow between in-patient and out-patient wards (the same patients were both places and could only participate once). To ensure *data rigor* the research team followed the organisations and looked for organisational and structural changes that could affect data collection. This was ensured in discussions with the managers and local coordinators at both sites. No major changes were detected during data collection.

Sampling adequacy is ensured by focusing on each method as an independent part of the study. For the qualitative studies, sample size was decided by the research team in discussion with the managers and healthcare professionals who assisted with recruitment in both hospitals

In addition, also followed by recommendations in the literature on satisfaction [167, 168]. In sub-study III, a non-participant observer was appointed as recommended by Jones and colleagues [167]. The non-participant observer collected qualitative data on power in the group discussions and observed during the entire consensus meeting. In the quantitative study, calculations of sample size were done by a biostatistician using power analysis.

With regards to *analytic adequacy,* validity and reliability in the quantitative analysis were described in paper III (chapter 5.4) [164]. For the qualitative approach, examples of the content analysis are provided in all articles, and several authors' contributions in the analysis process [175].

Applications to the *Analytic integration rigor* were performed in three ways: in a side-by-side mixed methods analysis in paper III [164] inspired by Creswell (2018) [140], by merging the results for sub-study I and II with the consensus process in sub-study III, and by integrating all findings in the discussion section.

4.4.3 Interpreting stage

Domain 4: Interpretive rigor

Interpretive rigor is a new language for the validation of a study. This domain consists of eight elements relevant for exploring if the findings in the study correlate with the conclusions: *interpretive transparency, interpretive consistency, theoretical consistency, interpretive agreement, interpretive distinctiveness, interpretive efficacy, interpretive bias reduction and interpretive correspondence [174]*.

In this thesis all analyses have been done for each method with additional results described for each. This was done before the side-by-side mixed methods results are presented in the discussion section in paper III. The latter creates a link between data quality and inference (design quality

and authenticity of conclusions) which applies to *interpretive transparency*.

To ensure *interpretive consistency,* inferences in the results for each analysis were discussed by the research team. A member check was carried out by presenting the results to individual managers and healthcare professionals in both case hospitals. This gave the participants the opportunity to respond to the findings. This created an *interpretive agreement* in the analysis with feedback and response from other researchers, managers, healthcare professionals, next of kin, and other stakeholders.

The Organizing for Quality framework [1] was the theoretical backdrop in all three sub-studies. The framework was tested and developed in all sub-studies, from the interview guides in study I, development of a revised framework adjusted to empirical finding from the cancer care setting in sub study II, and the guide development for the cancer care setting in sub-study III. This ensures *theoretical consistency* throughout this thesis.

Interpretive distinctiveness has been ensured by triangulation of methods and research findings, and with close discussions in the research team regarding assumptions of the results hypothesis (next of kin would report high satisfaction of care). The research team ensured *interpretive efficacy* with discussions of embedded research and how it could affect the findings, resulting in several discussions of the findings within and across the sub-studies.

Interpretive bias reduction has been handled by describing limitations for each sub-study in the papers, and in the side-by-side mixed methods analysis. Any convergences or differences between quantitative and qualitative findings were noted.

Interpretive correspondence needs to be addressed by other readers of this thesis, but from the author's point of view the aim and research

questions in the thesis have been answered with methods and analysis that corresponded well.

Domain 5: Inference transferability
This domain reflects the degree to which conclusions of the study can be applied to other settings. For the quantitative part, this domain refers to external validity and for the qualitative part it refers to transferability [174]. *Transferability* has been ensured with in-depth descriptions of next of kin role and involvement in the cancer care context. Challenges of involvement in hospitals have been described in relation to quality and safety. Furthermore, the Norwegian health care context and the cancer care context have been described. The details of hospitals, departments, participants, recruitment process, units of analysis and results are provided as permitted by ethical considerations. This could help readers to assess the relevance and transferability to their own setting.

External validity was ensured with a consecutive sampling strategy [133] consisting of recruitment of 250 next of kin in each hospital from November 2016 to November 2017. The FAMCARE instrument was found to be a valid and reliable instrument for measuring next of kin satisfaction with advanced cancer care in Canada with criterion validity from the McCusker scale, Cronbach's alpha and a 24-hour test-retest reliability. To address methodological issues with measuring next of kin satisfaction, we embedded open-ended questions as recommended by Willies and colleagues [176].

4.4.4 Disseminating stage

Domain 6: Reporting quality
This domain consists of element items relevant for describing if and how the study has been completed: *report availability, reporting transparency and yield (knowledge gained) [174]*.

Report availability: This thesis is carried out as planned and there are no delays in the planned dissemination of the results. However, data collection in sub-study II took longer than expected. This did not delay the thesis but resulted in further exploration of the inductive analysis in sub-study I. Paper II was written and embedded in the thesis. This paper was not described in the original thesis project plan from 2015.
This thesis has *reporting transparency* with the use of guidelines for accurate reporting of mixed methods studies (GRAMMS) [171]. It describes and justifies the mixed methods design, showing transparency in both the qualitative and quantitative components. The merging and integration of results have been carried out for each sub-study and the thesis. In addition, the results were tested with stakeholders in sub-study III. The study has resulted in four peer reviewed papers with reviewer comments that have improved paper quality.

4.4.5 Application in the real world

Domain 7: Synthesizability
This domain addresses how the synthesised evidence translated to the intended context [174].

This thesis has tested "The quality framework" for quality assessment in mixed methods research [173, 174]. With close descriptions of triangulation, discussions, presentation of research findings, and integration of stakeholders in all stages of the mixed methods study this creates a foundation for translating knowledge from this study back to the hospital cancer care setting.

Domain 8: Utility
This domain is about how policy makers and stakeholders use the research findings.

The next of kin involvement guide in paper IV is created to support managers and healthcare professionals in hospital cancer care to overcome challenges in next of kin involvement and to organise their involvement. The guide can be used as a reflexive tool for organisational improvement or to develop and improve practice. The guide emphasises the next of kin role for quality and safety in cancer care and has the potential to change practise towards more sustainable involvement of next of kin with development of sound methods and tools in the setting of the hospital cancer care.

4.5 Research ethics

This study has been approved by the Regional Committee for Medicine and Health Research Ethics in Norway (REK). Reference number 2015/1488 (Appendix 1). All participants in sub-studies I and II signed informed consent to participate in the study. For study III all participants approved their participation by email.

Sub-study II was the main concern in the study. The first part of the questionnaire survey planned for this sub-study consisted of variables with information on both the patient and the next of kin. On REK's request, next of kin in this study were recruited with patient consent. The consent was obtained by asking the patient for permission to recruit the next of kin they appointed. The questionnaire was anonymously conducted. REK approved that consent was considered obtained when the next of kin had filled out the questionnaire.

The project applied for approval to REK with two change notifications. Date for approval of the changes from REK:

- 21.10.15: small change in the interview guide (Appendix 2).
- 03.10.16: an increase in the number of research participants (300 /hospital), consent from next of kin and registration of a bio statistician as researcher in the project (Appendix 3).

In accordance with the Personal Data Act, the project has also been approved by data protections officers at both case hospitals (Appendix 4).

The researcher's role in embedded research

Guidelines for Research Ethics in the Social Sciences, Law and Humanities [177] are tools for researchers to identify relevant ethical considerations and promoting good scientific practice in research. The main challenge in this study (related to the guidelines) has been "Defining roles and responsibilities."

In this thesis the main researcher has a dual affiliation with an academic institution and with one of the case hospitals. This required a clear definition of roles to preserve a critical perspective [175]. Having a close relationship with the SHARE-Centre for Resilience in Healthcare at the University of Stavanger was very helpful. There were regular discussions of role definition with the three supervisors, the statistician, colleagues outside of the healthcare sector, and also in a PhD seminar on the role of access and embedded research led by a professor of sociology at the UiS. This experience is in line with other studies showing the importance of embedded researchers having strong links with academic institutions to ensure a critical perspective in their own research [175].

Research also describes the importance of a good collaborative relationship with the organisation [175]. Two of the researchers in the research team had affiliations at both hospitals' clinical practice. This has been a benefit for recruitment in all stages of the study and for the hospitals to prioritise the study over the six years. The close relationship with the organisations resulted in a shared publication with authors in the two hospitals (paper IV).

Incorporating the researcher's experiences can however have both drawbacks and benefits [178-180]. It can be problematic in terms of imposing assumptions. This could happen if the researcher does not have

a clear sense of role and presumptions of the studied field. Reflexivity has been a vital part of this study. As a cancer nurse with twenty years of clinical practise, my practical experience will always influence my healthcare research and require me to be vigilant to any potential bias.

Examples of such reflections could be, on the one hand, if the researcher is both a colleague, friend and a researcher; this can affect the research [181, 182]. The close relationship can give an even deeper reflection of the questions in the interview because the participant does not need to explain how the system works, culture, organisation, basic procedures, or situations [175]. But on the other hand, the relationship between the researcher and the participant can have negative consequences on the interview, for example, if the researcher has pre-assumptions of the participant [181, 182]. If they work closely together, power issues can arise if the researcher is a manager in the department. There can be privacy issues based on a relationship outside work or the possibility of violating confidentiality. In addition, it can affect the trustworthiness of the research, because the participants can hold back important information that could affect the results [183, 184].

In summary, this thesis has reflected and critical viewed ethical principles within the research team and in consultation with experienced researchers outside the research team. In addition, several iterations have been done with both hospitals' managers and staff, and with the main researcher's academic institution. One of the results of this discussion was that three interviews were conducted by other researchers in the research team to avoid conflicts of interest. In addition, all participants have been informed that they have the right to withdraw at any stage in the interviews if they feel any discomfort with the relationship, the questions or anything that might affect the interview. They have also been informed that their withdrawal will not affect their current or future employment.

In line with other researchers' experiences of embedded research [175, 179], this thesis support that if preconceptions are handled as a natural part of the research process by discussing closeness and distance to the research field regularly with the research team and others outside the field studied, it could bring a valuable component to the study with potential of mobilising knowledge and increasing impact of research as described by Marshall and colleagues [178, 179].

5 Results

This chapter presents the results of the four papers in the thesis. A summary of the results and the relationship between each paper is presented. The chapter ends with descriptions of patterns across sub-studies with the Organizing for Quality framework as a guide.

5.1 Sub-study I - Paper I

Next-of-kin involvement in improving hospital cancer care quality and safety: a qualitative cross-case study as basis for theory development [145].

Paper I reports findings from a comparative multiple embedded case study of cancer departments in two Norwegian university hospitals whose aim was to explore how managers (13) and healthcare professionals (19) understand the role of next of kin in cancer care, and what methods they use for next of kin involvement. The study explored the influence of next of kin involvement on quality and safety improvement within cancer care in hospitals.

Data collection consisted of analysis of national policy documents, and interviews with managers and healthcare professionals collected in 2016. A directed content analysis [154] was conducted for the qualitative interviews guided by the theoretical framework Organizing for Quality [1].

Result showed that healthcare professionals in both hospitals were aware of the national policy and expectations of more structured next of kin involvement. However, even if managers and healthcare professionals valued next of kin involvement, there were only a few formal or systematic approaches to involvement. There was no plan to operationalise a strategy for involvement. Interdisciplinary collaboration was found to be a success factor for involvement of next of kin in both

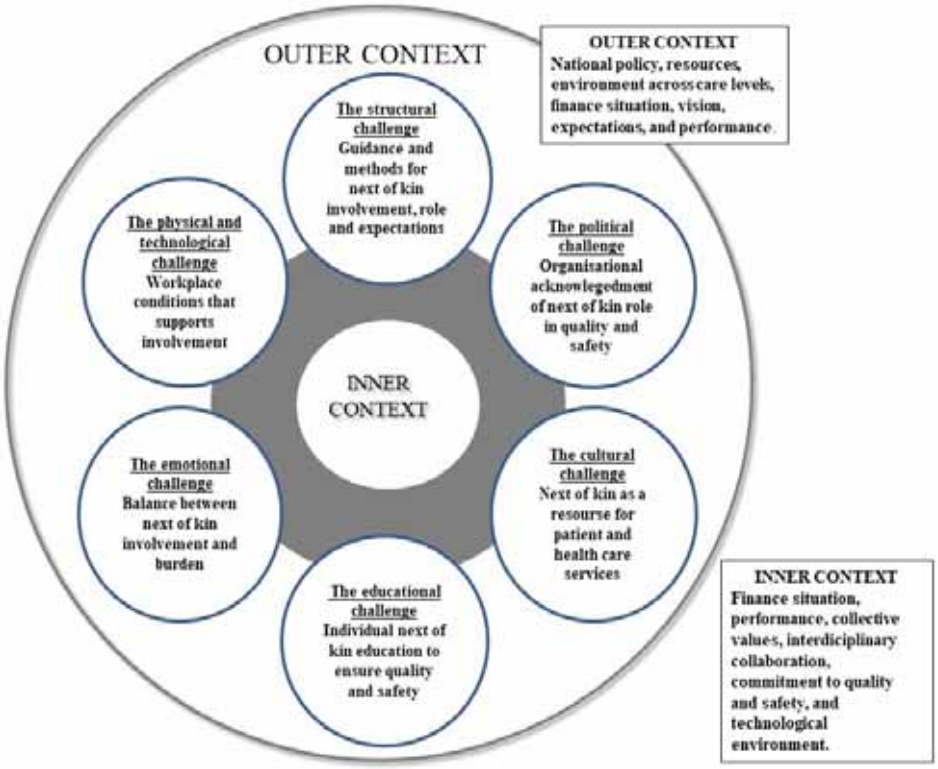
hospitals. However, the study showed a lack of interdisciplinary arenas leading to interdisciplinary differences in the conceptualisation of quality and safety between the professional groups e.g. on how much information is enough to provide to the patient and next of kin before chemotherapy treatment.

In both hospitals, healthcare professionals pinpointed that it was a balance between involving and using the next of kin as a practical resource because of capacity problems in the department. The results indicated that healthcare professionals depended on the next of kin when there was understaffing or an organisational challenge. Healthcare professionals described few next of kin education activities in the hospitals. Results also showed that quality champions in the departments had to struggle against the management to prioritise quality projects or academic projects due to patient overload and lack of qualified healthcare personnel.

In addition, the results showed how a lack of systematic approaches to next of kin involvement added to the healthcare professionals' emotional stress. This was conveyed as they individually set the priorities in the shifts depending on performance and available resources. Even if it was done correctly, it could still feel wrong and create an emotional challenge for the healthcare professionals.

Managers and healthcare professionals at both sites argued that a more structured way of guidance could improve the role of next of kin in quality and safety. In our study the informants noted nine areas where next of kin were important for cancer care service quality and safety. These areas were information, pain treatment, transitions, observations, motivation and emotional support, physical activity and rehabilitation, daily care, nutrition, and palliative and terminal care. This study highlighted the importance of next of kin involvement in cancer care. The next of kin role cannot be replaced by other stakeholder groups in healthcare, so more effort should be placed on developing systematic

approaches for involvement in hospital cancer care. Based on the findings the authors suggested directions for more systematic approaches in the hospital cancer care field by presenting a modified Organizing for Quality model for the cancer care setting (Model 1).



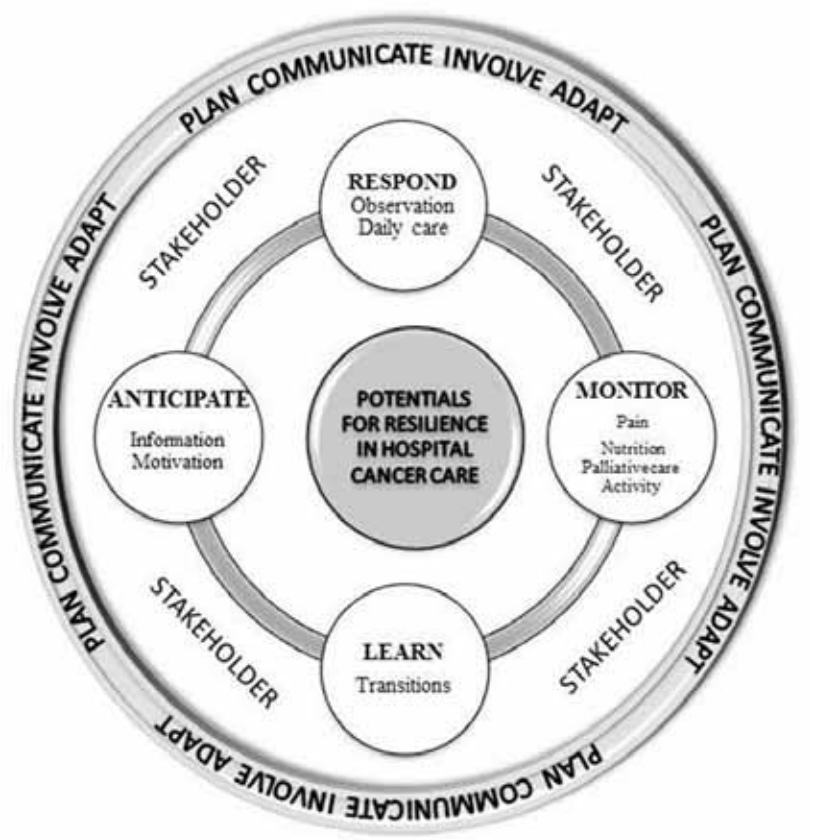
Model 1. Modified Organizing for Quality model for the cancer care setting (From paper I, III) inspired by Bate and colleagues [1].

5.2 Sub-study I - Paper II

Resilience from a stakeholder perspective: The role of next of kin in cancer care [146].

Paper II reports findings from the same comparative multiple embedded case study as paper I. Data collection was the same, but the data was subjected to directed content analysis [154] according to Hollnagel's four resilience potentials [76]. The paper explored the stakeholder perspective in cancer care and presented new knowledge on how next of kin can be co-creators of Resilient health care.

The paper described how next of kin were co-creators of resilient performance in hospitals and complement healthcare professionals in all four potentials for resilient performance as depicted in Model 2.



Model 2. Next of kin contribution in hospital cancer care (from paper II).

Results showed that observations done by next of kin helped the healthcare professionals to **respond** more quickly to changes in the patient's condition and to make confident rapid care decisions because of information provided by the next of kin. When patients who were potentially at high risk of serious side effects of the chemotherapy were discharged, having a next of kin at home who could respond on their behalf was described at least as important as having other healthcare professionals in the municipality.

The results also showed that the next of kin were often assigned care tasks either by themselves, by the patient, or by healthcare professionals. These tasks consisted of **monitoring** the patient's medication, nutrition,

daily care, observation and rehabilitation. The healthcare professionals noted that the next of kin know the patient best and can sometimes guide the patient and encourage the patient, for example to eat. Healthcare professionals considered the next of kin to have an extra capacity to motivate the patient to be more physically active. In palliative and terminal care, the next of kin have a natural role in daily activities and in care. Healthcare professionals described educating the next of kin to look for changes in the patient's condition, and how to respond to needs and wellbeing of the patient.

The healthcare professionals in this study observed that they could **learn** more from the experiences and perceptions from next of kin, particularly to understand more about what hospitals can do to provide safer care for cancer patients related to transitional care. This is in line with the descriptions of next of kin often having the capability to **anticipate** deterioration or treatment consequences because of their close relationship with and knowledge of the patient.

5.3 Sub-study II - Paper III

Measuring next of kin satisfaction with hospital cancer care: a mixed methods study as basis for improving quality and patient safety [164].

Paper III reports findings from a questionnaire study with responses from 238 next of kin conducted between November 2016 and November 2017. The aim was to explore next of kin satisfaction with hospital cancer care and identify next of kin's need for involvement in patient treatment and care. The paper has a mixed methods convergent design applying the 20-item FAMCARE scale as a survey instrument, and open-ended questions for qualitative analysis. Regression analysis, exploratory factor analysis and qualitative content analysis are combined.

In this study next of kin reported high satisfaction with care in both hospitals. The results showed a higher score on satisfaction with care (1.5,1.1-2.0), $p < .001$ (Wilcox signed test) than with involvement-related items indicating a lack of systematic approaches and sound methods of involvement to improve satisfaction and service quality and safety. In addition, the largest difference between the case hospitals was found in item Q15 ("The way the family is included in treatment and care decisions") with a 30% increased probability of being satisfied or very satisfied with hospital 1 (RR 1.3, 95% CI 1.1-1.7, $p = .013$). This finding indicates a significant difference between the case hospitals in how involvement of next of kin helps to improve satisfaction with care.

The content analysis of the qualitative data material with responses from the open-ended questions embedded to the survey (n=100) resulted in three themes. The first theme was *"Being on parallel information tracks"* describing important quality and safety measures in the cancer care trajectory from the next of kin's perspective. The next of kin remained the guardians for the patient, but to fulfil that role they argued that information adapted to their role, resources and capabilities were crucial. The second theme was *"Neither in nor out of the treatment processes"* and focused on the next of kin role, contribution, and possible impact on patient outcome. The respondents argued that they tried to act in the patient's best interest despite incomplete information and education. The third theme was "The act of balancing involvement needs." This theme linked the other two and described the importance of involving next of kin to improve their own satisfaction with care. In addition, next of kin in our study insisted that a private conversation with the healthcare team could increase their satisfaction with hospital cancer care.

This study revealed that next of kin should be acknowledged as an independent part of the patient's healthcare team, and not merely as part of the patient's role.

5.4 Sub-study III - Paper IV

Developing a Next-of-Kin Involvement Guide in Cancer Care – Results From a Consensus Process [169].

Paper IV reports a participatory consensus-based process based on a modified Nominal group technique (NGT) applied as a single one-day meeting with 20 stakeholders. The aim was to present the results from consensus process, and to develop a next of kin involvement guide based on the NGT process supplemented by earlier research findings (papers I-III). The research problem presented for the expert panel was: "What topics and elements should be included in a next of kin involvement guide to support quality and safety in hospital cancer care?" The results represent the relationship between the papers by using the results from Papers I, II and III in Paper IV.

The paper presents key topics and elements that can guide next of kin involvement initiatives to improve quality and safety in hospital cancer care. The results of the top five priorities contend that next of kin are key stakeholders in quality and safety. The panel emphasised the importance of building systems for gathering experiences from next of kin, formally integrate next of kin experiences in a feedback loop for service development, tailor next of kin training and support, and create a culture that considers next of kin involvement as a prerequisite for sound patient care.

The study integrates these aspects by presenting the consensus-based involvement guide, developed for use in clinical practice in hospital cancer care. The guide builds on earlier theory development of the Organizing for Quality framework (see Model 1), adjusted and refined

for the cancer care setting with the integrated priorities identified in this sub-study (Figure 5).

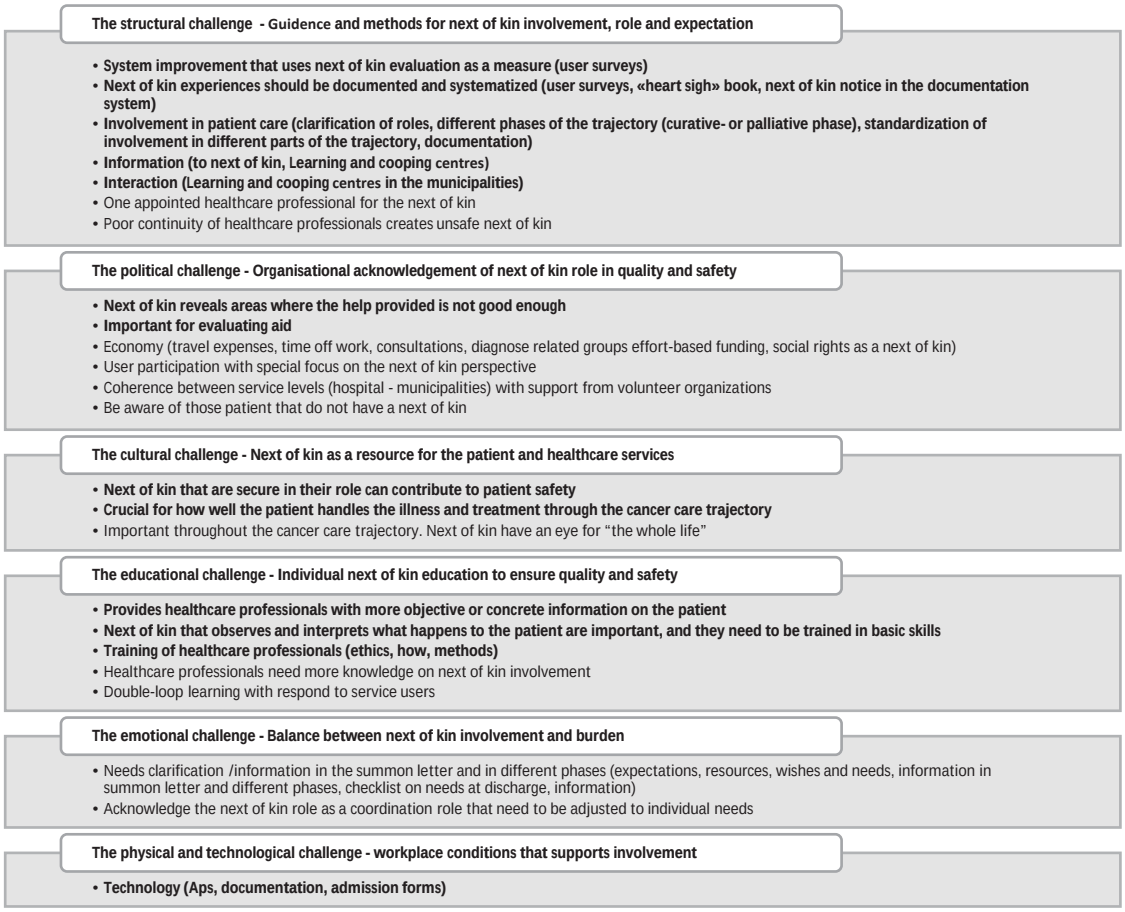


Figure 5. Organizing for Quality and safety: a next of kin involvement guide (from paper IV).

5.5 Patterns across sub-studies

Patterns across the four papers was guided by the six challenges in the Organizing for Quality framework [1]. The goal of this synthesising of categories was to determine the relationship between perspectives from

healthcare professionals, managers, and next of kin. Using the modified Organizing for Quality six universal challenges as a framework (See Model 1 for overview) for finding patterns across sub-studies in the thesis, revealed two common categories. These two categories emerged in all three sub-studies:

- The structural challenge - Guidance and methods for next of kin involvement, role, and expectations
- The cultural challenge - Next of kin as resources for patient and healthcare services.

Furthermore, a third category indicated an emotional challenge for managers, healthcare professionals, and next of kin related to next of kin involvement in hospitals. These findings were not consistent and were therefore considered weaker than the structural and cultural challenge. However, the emotional challenge mirrors an important complexity in next of kin involvement from both perspectives that merits more attention:

- The emotional challenge - Balance between next of kin involvement and burden.

Table 5 summarises the six universal challenges and common sub-categories from papers I-IV. The papers each illuminates different aspect that answers the research question for this thesis (chapter 2.7) conceptualised as follows; challenges (paper I), potentials (paper II), role (paper III), directions (paper IV). All the challenges in the Organizing for Quality framework are not found at this level of abstraction, as we can see in the table with the responses “No findings” for the political-, educational, and physical and technological challenge. These challenges are evident in the findings in the respective papers and more information on these specific challenges can be found there. However, for the common patterns across all papers the next chapter will discuss these findings.

In summary, this thesis' findings across the four papers demonstrate that organising next of kin involvement is lacking in hospital cancer care due to limited established structures and few available methods for involvement. This is found in the perspectives of healthcare professionals (papers I, II,) and the next of kin's perspective (papers III, IV). Moreover, there is a clear understanding that next of kin is a substantial resource for cancer care patients and can be instrumental in ensuring quality and safety of healthcare services. However, the culture for involving on a continuous basis with the purpose of quality and safety is still underdeveloped (papers I, II, III, and IV). Paper IV illustrates how the perspectives of next of kin, healthcare professionals and managers takes advantage of a joint collaboration on prioritising and organising for involvement in cancer care services to handle the challenges identified by healthcare professionals and managers in paper I and II and next of kin in paper III.

Paper I Challenges	Paper II Potentials	Paper III Role	Paper IV Directions	Paper I, II, III, IV Common categories
Lack of systematic approaches for next of kin involvement Next of kin as quality and safety resources	Next of kin's ability to observe, guides care decision maker's response Next of kin watch over medication and nutrition in patient care Next of kin oversee patient activity level Watching patient signals in palliative and terminal care Key role for safe transitions across care levels Next of kin foreseeing possible deteriorations and treatment consequences	Being on parallel information tracks Neither in nor out of treatment processes Acting in the patient`s best interest The proactive approach	Guidance and methods for next of kin involvement	The structural challenge
Next of kin as an equal partner and a practical resource	Dependency of next of kin in daily care to respond quickly	Guardians in the cancer care trajectory	Next of kin as a resource for the patient and healthcare service	The cultural challenge

Paper I Challenges	Paper II Potentials	Paper III Role	Paper IV Directions	Paper I, II, III, IV Common categories
Unspoken expectations of next of kin performance and emotional stress The difficult duty of confidentiality	No findings	The act of balancing involvement needs	Balance between next of kin involvement and burden	The emotional challenge
Lack of interdisciplinary collaboration hampers next of kin involvement The difficult duty of confidentiality	No findings	No findings	Organisational acknowledgement of next of kin role in quality and safety	The political challenge
Limited systematic next of kin education	No findings	No findings	Individual next of kin education to ensure quality and safety	Educational challenge
Location and infrastructure affect possibilities for next of kin involvement	No findings	No findings	Workplace conditions that support involvement	Physical and technological challenge

Table 5. Patterns across sub-studies

6 Discussion

The aim of this thesis was to explore the role of next of kin for quality and safety in hospital cancer care and to develop a consensus-based involvement guide. This chapter discusses the mixed methods synthesis of findings with attention to the patterns across the thesis in light of previous research and theoretical perspectives.

6.1 Next of kin as quality and safety resources in hospitals

Next of kin are quality and safety resources in hospital cancer care, according to healthcare professionals and managers (paper I, II, IV), and next of kin (paper III). In addition, in line with others, this thesis reveales that healthcare services fail to involve next of kin in cancer care sufficiently and that healthcare professionals lack effective tools and strategies to support meaningful involvement [25, 26]. Despite findings that next of kin are such essential parts of everyday work in hospitals' cancer care, limited attention is given to the next of kin role for quality and safety in cancer care [24, 185].

This thesis describes how next of kin often are the first responders to changes in the patients' condition. Healthcare professionals explained the different roles of next of kin in hospital cancer care in relation to patient care, quality and safety (e.g., observation, monitoring medication, overseeing activity, watching symptoms, ensuring safe transitions, and foreseeing possible deteriorations and treatment consequences) (papers I, II, IV). Similar findings have been described by others [71]. Nevertheless, the thesis' findings on how next of kin are possible actors in creating and upholding resilience by complementing healthcare professionals in closing the gap on potential treats of patient safety in cancer care is new. The findings contribute to a new perspective on how stakeholders, such as the next of kin, shape resilience in health

care [73, 78]. Next of kin were active in anticipating, monitoring, and responding, and learning in cancer care, in close collaboration with service providers and the patients (paper III) [74, 76].

An important paradox is that next of kin describe *acting in the patient best interest* but *feel neither in nor out of treatment processes* (paper III). Previous literature has demonstrated that research on methods and tools within this field is still fragmented [15]. This thesis' findings support this notion and uphold the importance of identifying new intervention methods for involving next of kin in cancer care [42, 186]. Based on these findings, next of kin need solutions, information, and customised training (paper III). This will require a change in organisation of cancer care services by giving more attention to the next of kin in parallel with the patient (paper III) [1, 78]. It might be possible to use the modified Organizing for Quality framework for cancer care (papers I and IV), and the next of kin involvement guide (paper IV) to help seeing the next of kin as a resource, evaluate performance, and target directions for next of kin involvement adjusted to everyday challenges and opportunities.

6.2 The structural challenge in hospital cancer care

Next of kin's contribution to quality and safety is evolving as an important area of investigation in complex adaptive systems such as hospitals [72]. In these systems, people adapt and act in response to what happens in their everyday work [118]. The patient and healthcare professionals are natural actors in these systems, but descriptions of the next of kin dimension is lacking both in relation to theories of Resilient health care and complex adaptive systems [72, 117, 119].

In the case hospitals in this thesis, there were no systematic approaches for next of kin involvement. There were only a few systematic efforts for involvement across the two cases (e.g., summon letter, first consultation, courses (papers I, II, IV)). This presents a large structural challenge for

hospital cancer care [1]. Not only to meet the governance policy of more systematic next of kin involvement [7, 9, 187], but also to reflect this thesis' voices from next of kin who are requesting more proactive solutions for their systematic involvement to support the patient and contribute to the service quality and safety (papers III,IV).

In line with the Organizing for Quality framework [1] this thesis provides guidance for a structural change through the involvement guide (paper IV). The guide is theoretically [1, 101] and empirically anchored, and designed for managers and healthcare professionals in hospital cancer care with suggestions of: system improvement; using next of kin evaluation as a measure; documentation of next of kin experiences; involvement in patient care; provision of information; and interaction with support bodies such as learning and coping facilities in the municipalities (paper IV). Such a guide has been lacking in cancer care. In collaboration with next of kin, healthcare professionals, and managers, this thesis lays the foundation for future testing and improvement. The guide needs to be tested and refined to the external context (regulations, demands, resources) and internal context (resources, economy, motivation, work plans) of the hospitals. To ensure sound next of kin involvement in hospital cancer care, the hospitals need to meet the structural challenge [1] with plans, responsibility, procedures and systems that supports this thesis findings. Guides that are theoretically grounded and consensus-based, as the next of kin involvement guide, have the potential to reduce the gap between Work as imagined and Work as done [123] through collaboration [188] with all affected actors in the healthcare systems [189, 190]. The consensus process in this thesis (paper IV) could be an inspiration of a method on how multiple stakeholders in healthcare can contribute on equal terms in identification of quality and safety challenges and agree on how to overcome these in practice.

Future research should strive to explore next of kin as an equal partner in the medical team around the patient. The cultural dimensions [1] will

first and foremost be of interest for the latter, but also the role of stakeholders in Resilient health care could additionally be explored further in relation to structural change and culture. Other frameworks of Resilient health care with a key interest of stakeholder involvement such as the Integrated Resilience Attributes Framework [128] could also contribute to a deeper understanding of the stakeholder perspective (paper II) in the field quality and safety.

6.3 A balance between next of kin involvement and burden

Next of kin involvement in healthcare is complex [46, 50]. Research shows that becoming a next of kin can have serious consequences [26, 44, 45, 47]. There are psychosocial and ethical implications involved in the next of kin role, such as distress, anxiety or depression [24, 54]. This relates to the emotional challenge in Bates and colleagues' framework [1]. According to the Organizing for Quality framework, the emotional challenge needs to be acknowledged and acted upon in work on quality and safety in hospital cancer care.

This thesis mirrors earlier research [50, 191] and argues that more systematic involvement in cancer care may have positive consequences in terms of reducing the stress and anxiety of caregiving by increasing involvement in decision-making processes (papers III, IV). This thesis has not explored the topic of treatment burden and its consequences, but the findings reveal this as a key topic in relation to next of kin involvement in quality and safety in cancer care, and therefore merits future investigation.

More systematic involvement in care is not necessary the same as more care tasks for the next of kin. On the contrary, one may argue that by customising interventions to the individual patient and next of kin needs, it will help to balance involvement and burden (papers I, II, III, IV). By acknowledging next of kin involvement, it is possible to translate

research findings through methods and tools that are useful for the involvement of patients, healthcare professionals and next of kin (papers III, IV) [42, 192]. As an example of how to take advantage of next of kin's experiences without adding more tasks, it is possible to measure next of kin satisfaction with care, as done in this thesis (paper III). The results can be used as an indicator of quality and safety for cancer care on a ruinously basis, for example embedded in the already existing patient user surveys conducted in the hospitals (Paper I) [57]. Not only could this improve quality of care, but in a Resilient health care perspective for healthcare professionals, this could be a potential way to learn from what goes well related to measures of satisfaction with their performance in everyday work [76, 130, 193]. This approach would also be in line with national plans and strategies in Norway that state that next of kin should be acknowledge and involved [7, 9]. For hospital cancer care, these finding of what possibilities that lie in the wake of more systematic involvement of next of kin should be recognised and acted upon. This thesis' findings indicate that the lack of systematic involvement of next of kin creates emotional distress for healthcare professionals and next of kin (papers I, II, III). This is an emotional challenge related to create a balance between involvement and burden for the next of kin (papers III, IV), but also a cultural challenge of acknowledging next of kin as resources for the patient and for healthcare professionals. Such an acknowledgment could reduce negative emotional stress for healthcare professionals (I, II). In line with other studies [194-196], this thesis indicates a growing concern for quality and safety if the emotional stress continues and reduces the attention from the high risk treatment and care provided by cancer facilities (papers I, II, IV) [194]. This aspect should be further investigated.

6.4 Key contributions for theory development and cancer care practice

This thesis is a contribution within the currently underexplored field of next of kin involvement in relation to quality and safety in cancer care [69, 73, 77]. The thesis has three major contributions as depicted in figure 6. **1)** The revised Organizing for Quality framework for the hospital cancer care setting in Model 1 (paper I), **2)** The stakeholder potential in Resilient health care (paper III), and **3)** The next of kin involvement guide for clinical practice.

The first two contributions relate to theory development; the third relates to preparing knowledge translation into clinical practice by developing a next of kin guide.

Figure 6. Thesis contributions for theory development and practice

All three contributions are relevant for theory, intervention development, and practice improvement. The contributions integrate theories from the quality improvement [1] and safety fields [76].

Several reviews from the Resilient health care literature have argued that resilience research needs new methods for exploring and supporting resilient health care [82, 109, 124]. This thesis has developed a guide for healthcare professionals and managers to support involvement of next of kin in cancer care practice. The guide can support adaptations needed in cancer care practice. The findings in this thesis support that resilience in healthcare depends on the potentials described by Hollnagel [76]. It

shows how different stakeholders support the four potentials by compensating for weaknesses to prevent adverse events from developing and to uphold quality of services e.g. during peak hours and in transitions between service levels (paper II). The thesis argues that there is a need for further exploration of the role of different types of stakeholders in resilient health care, beyond next of kin.

The guide developed in this thesis can support resilient performance. By bringing together key stakeholders of healthcare professionals, managers, and next of kin, the guide can create a reflexive arena that may contribute to learning and improvement through involvement of next of kin (paper IV). This is relevant for establishing arenas for sharing knowledge and experiences as pointed out as measures in the national plan to enhance quality and safety in Norwegian healthcare services [98].

This thesis shows that by integrating findings across theoretical approaches (Organizing for Quality framework, Resilient health care), new perspectives relevant for theory development for both the quality (revised model for the hospital cancer care setting) and safety fields (stakeholder potential in resilience) can emerge. In this way this thesis broadens the insight on how and why quality and safety should be explored together when investigating large complex adaptive systems, such as hospitals [72]. Furthermore the thesis has the advantage of data from healthcare professionals, next of kin, and managers, conducted with different methods, which is required for a full understanding of the phenomenon [1]. Future studies in this field should to a larger degree strive to integrate mixed methods designs with several stakeholder groups.

For clinical practice in hospital cancer care, the expert panel (paper IV) was clear in its conclusions of the consensus process. *Next of kin that are secure in their role can contribute to patient safety* and can *be crucial for how well the patient handles the illness and treatment through the cancer care trajectory.* Integration of the next of kin involvement guide

has the potential to improve quality and safety for cancer patients in hospitals. The guide also integrates concepts from quality improvement [1] and resilience literature [76], by refining the theoretical framework and contextualising it into hospital cancer care (papers I, II, IV). However, there is still a way to go before implementation and translation of the thesis research findings are integrated into clinical practice. Further research should test the guide in a clinical context with programme theory and evaluation of process and outcome.

6.5 Towards a new era for stakeholder involvement

While this thesis was being written, the research field has developed. There are now strong signs that the field is entering a new era in research and clinical healthcare practice where stakeholder involvement is more prominent than ever. From the macro and meso level, this comes with strong recommendations, strategies and plans for involvement of next of kin and other stakeholders [7, 10, 98, 126]. Moreover this is seen, by acknowledgement of the potential to improve healthcare quality and safety through involvement [73, 74, 146, 197, 198], and the stronger focus on patient and stakeholder involvement in research activities [84, 199]. Last but not least, involvement is now seen to a stronger degree in diverse councils and quality committees in organisations, and on an everyday basis in the microlevel of hospitals [17].

In line with the strong focus on stakeholder attention, a recent report by Leveson [200] suggests a Safety III approach as a way forward in safety science. This critique of Safety I and II provides a new safety definition that includes the stakeholder perspective, identified as the “system stakeholders” [200]. This thesis echoes the need for clarification and acknowledgement of stakeholder involvement in safety research.

In light of the COVID-19 pandemic, there is a need to understand the adaptive capacity of stakeholders for keeping the patient safe, by

learning from successful outcomes in cancer care setting [77, 194, 201]. The stakeholder potential in Resilient health care (paper III) is promising, and further studies should investigate it in other settings. Moreover, the adaptive capacity of next of kin and other stakeholders is demonstrated in this thesis (papers I, II, III, IV) through the handling of the quality challenges.

6.6 Methodological reflections

A mixed methods case study involving qualitative and quantitative methods was chosen. This is a comprehensive design and her I reflect on key decisions and challenges in the research process.

Stakeholder involvement in research has been approached with a combined consulting and collaboration strategy [202]. The research team has consulted and collaborated with stakeholders in all phases of the study and sought guidance, knowledge, and advice for the decision-making processes in the study. In retrospect, the project could have chosen a different strategy that involved even stronger collaboration with active stakeholder groups and a larger sample of next of kin representatives, in a panel, as active co-researchers throughout the project, or in the design of the project. However, stakeholders in this thesis are defined broadly. The close collaboration with hospital managers, healthcare professionals, the local coordinator in Hospital B, representatives from learning- and cooping centres, and next of kin representativeness in the survey and in the consensus process ensured confirmability. Further, it also set the agenda for how and why decisions were made.

I interviewed managers and healthcare professionals in the first study. It cannot be ruled out that if next of kin interviews were conducted first or an observational study was performed as a first stage of this project the result might have been different. However, next of kin are a vulnerable group as pointed out by the Regional Committee for Medicine and

Health Research Ethics in Norway, and both interviews and observations could be demanding. The survey chosen for study II was a way to spare them a type of participation that could be difficult to decline. The survey provided rich data material. By embedding qualitative text variables, it allowed the next of kin to elaborate on their responses in their own time with some time constraints.

The consensus process allowed participation of all stakeholder groups; however, the representativeness of next of kin and medical doctors could have been larger. Nevertheless, the size of the panel was manageable, and the moderators focused on a balanced discussion where all participants' voices could be heard. In addition, to show that this was real and sensitive, a non-participant observer provided the moderators with valuable input on factors that could have affected the process. The anonymous voting also was a way to ensure that the participants could give their input and speak freely.

The choice of theoretical perspective could also be considered a limitation and a strength. The selection of Organizing for Quality framework [1] to guide the interview guides, analysis and involvement guide development could limit the participants in their elaboration on next of kin involvement and another theoretical framework from safety science [93] or from established patient and public involvement literature [84, 199], could have resulted in a different approach and findings. However, using the established Organizing for Quality framework, which have been used as a basis for previous guide development, was considered a strength. In addition, the use of Resilient health care theoretical lenses supplemented the theoretical perspectives and interpretation of data.

The choice of the FAMCARE survey instrument could be considered a limitation and a strength. There is no survey instrument found with a full match on the thesis theme, and therefore FAMCARE was chosen as it addresses several relevant aspects. The FAMCARE focuses on

satisfaction with care and a new survey instrument could have been developed and tailormade to the role of next of kin involvement in quality and safety in hospital cancer care. However, this was not the purpose of the thesis, and the translated and validated FAMCARE instrument proved relevant for our study. The added qualitative open-ended questions ensured sound adaptation to the thesis.

7 Conclusion

This thesis offers new insight into challenges, potentials, roles and directions for next of kin involvement in hospital cancer care in light of theories in the quality and safety research field.

The thesis contributes with theory development in the quality and safety research field, but also practical guidance for managers and healthcare professionals in hospital cancer care with a consensus-based guide for next of kin involvement. Findings in the thesis broadens the understanding of the next of kin role as a complex social phenomenon, both interconnected with all actors in the healthcare system and at the same time conceptualised as an independent feature of interest in research and clinical practice.

The thesis has demonstrated that next of kin hold a vital role for quality and safety in cancer care in the two case hospitals (e.g. transitions, palliative care, pain treatment, motivation, daily care). It also illuminates that hospital cancer care lacked systematic next of kin involvement in the organisation of healthcare services. In addition, tools and guides for sound next of kin involvement in hospitals were missing. There was however a substantial agreement from hospital managers and healthcare professionals that next of kin to cancer patients are resources and help hospitals to ensure quality and safety of the services. By identifying suggested methods for involvement (e.g. system improvement, user surveys, one appointed healthcare professional for the next of kin, closer interaction with support bodies) from the managers', healthcare professionals' and next of kin perspectives, and by integrating these into the Next of Kin Involvement Guide (Figure 5.), the thesis contributes with a requested tool that have the potential to support managers' and healthcare professionals' future working on quality and safety in hospital cancer care.

7.1 Implications for practice and future research

The findings of this thesis provide applicable implications for next of kin involvement in hospitals. These should be recognised not only by hospitals, but also by policymakers, the public, and researchers. The findings demonstrate challenges, potentials, roles, and directions for next of kin involvement, and for possible improvement of quality and safety in hospital cancer care.

7.1.1 Implications for practice

- Develop goals for systematic next of kin involvement in cancer care.
- Strive to base decisions and actions on a multi-stakeholder approach within the cancer care setting.
- Create arenas for hospitals to share ideas and learn from each other.
- Provide reflexive spaces [203] as a learning arena across organisations, disciplines, and service levels within the hospitals with the use of the consensus technique.
- Pilot test and implement of the next of kin involvement guide (Paper IV) along with evaluation.
- Focus effort on the cultural dimension and acknowledgement of next of kin as an equal and independent partner in cancer care.
- Measurement of next of kin satisfaction as an indicator used to improve hospital cancer care services.
- Establish routines for conversation for next of kin without the patient focus.
- Develop quality indicators focusing on next of kin satisfaction with cancer care and proactive approaches in line with Resilient health care [76, 128, 193] and Organizing for Quality [1] thinking on structure, culture, and emotions.

7.1.2 Implications for future research

- There is a need for more research on next of kin` contribution to quality and safety in cancer care with a multi-stakeholder perspective [204].
- There is a need for research with mixed methods designs to investigate the multi-stakeholder Resilient health care.
- Qualitative research is recommended to investigate "the stakeholder potentials" in Resilient health care for fields such as dementia and mental health.
- Future research should also explore next of kin involvement in cancer care during a pandemic setting, as this is an area where services continues during significant stress from the crisis such as COVID-19 [194, 201, 205].
- Studies of next of kin involvement and co-creation of services are relevant and recommended for the homecare setting and in transitions between organisations, including support bodies in the municipalities and between levels of cancer care services.
- There is a need for testing and refinement of the next of kin involvement guide in hospital cancer care in larger samples of hospitals with different level of specialisation, and across countries in the next iteration.
- Further development of targeted methods and tools for involvement created with next of kin as research partners, is recommended.
- Future studies are encouraged to focus on developing quality indicators in clinical practice that integrates next of kin involvement in the measurement.
- As a tailormade survey instrument is lacking in this field, and future studies should develop and test a next of kin involvement survey for quality and safety in hospital cancer care.

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Part II

List of papers

Paper I

Bergerod, I.J., B. Gilje, G.S. Braut, and S. Wiig, *Next-of-kin involvement in improving hospital cancer care quality and safety - a qualitative cross-case study as basis for theory development.* BMC Health Serv Res, 2018, 18(1): p. 324.

Paper II

Bergerod, I.J., G.S. Braut, and S.Wiig, *Resilience From a Stakeholder Perspective: The Role of Next of Kin in Cancer Care.* J Patient Saf, 2020, 16(3): p. e205-e210.

Paper III

Bergerod, I.J., I. Dalen, G.S. Braut, B. Gilje, and S. Wiig, *Measuring next of kin satisfaction with hospital cancer care: Using a mixed-method approach as basis for improving quality and safety.* J Adv Nurs, 2020, 76(5): p. 1232-1246.

Paper IV

Bergerod, I.J., G.S. Braut, B. Fagerdal, B. Gilje, and S. Wiig, *Developing a Next-of-Kin Involvement Guide in Cancer Care-Results From a Consensus Process.* Cancer Nurs, 2020, Publish Ahead of Print.

Paper I

Bergerød et al. BMC Health Services Research (2018) 18:324
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BMC Health Services Research

RESEARCH ARTICLE Open Access

Next-of-kin involvement in improving hospital cancer care quality and safety – a qualitative cross-case study as basis for theory development

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Abstract

Background: Next-of-kin are an extension of healthcare professionals in all stages of cancer care. They offer care activities such as interpretations of symptoms, and reporting of negative or adverse effects of treatment, without any professional knowledge or skills. Their participation is often expected from healthcare professionals, managers, or the patient. However, there is limited knowledge of next-of-kin's role in and contribution to quality and safety improvement in hospital cancer care. The aim of this study was to explore how managers and healthcare professionals understand the role of next-of-kin in cancer care, and what methods they use for next-of-kin involvement.

Methods: The study design was a comparative multiple embedded case study of cancer departments in two Norwegian university hospitals. Data collection methods consist of qualitative interviews with managers (13) and healthcare professionals (19) collected in 2016, and document analysis of policy documents and regulation. The interviews were analyzed according to a directed content analysis approach guided by the theoretical framework 'Organizing for Quality'.

Results: Both hospitals have a strategy to involve next-of-kin in treatment and care but have no formal way of doing so. Managers and healthcare professionals in the two hospitals illuminated nine areas where next-of-kin are important stakeholders in improving quality and safety. These nine areas (e.g. nutrition, observations, transitions, pain treatment, information, palliative and terminal care) are common across the two hospitals. Key challenges in the next-of-kin involvement pertain to insufficient physical working conditions and room facilities, and lack of continuity of experienced nurses and consultants.

Conclusion: Hospital employees and managers regard next-of-kin as a safety net or a buffer that cannot be replaced by other stakeholders. This study shows a close collaboration between patient, next-of-kin and healthcare professionals in cancer care, but more effort should be invested in more systematic approaches for next-of-kin involvement in quality and safety improvement such as a guide for managers and healthcare professionals on methods and areas of involvement.

Keywords: Case study, Next-of-kin, Family, Caregiver, Quality, Safety, Quality improvement, Cancer, Hospitals, Cross case analysis, Theory development

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Background

Next-of-kin and especially family caregivers are an extension to the healthcare professionals and are often involved in all stages of the cancer care trajectory [1, 2]. Next-of-kin often provide care such as interpretations of symptoms, and reporting of negative or adverse effects of treatment, without any professional knowledge or skills. This participation is often expected from healthcare professionals, managers, the patient or significant others [3, 4]. A systematic literature review has identified more than 200 problems related to caring for cancer patients [5]. The Institute of Medicine [6] has highlighted next-of-kin as an important safety dimension in patient-centered care. A study published in 2017 concluded that cancer patients experience adverse events more often than other hospitalized patients [7].

There are limited descriptions of the methods and challenges in involving next-of-kin in improving the quality and safety of hospital cancer care [4]. A few studies on the role of next-of-kin in cancer care have demonstrated that some of the reasons for close interaction between next-of-kin and patients are related to quality and patient safety concerns. Sapountzi-Krepia and colleagues [8] revealed in their study that next-of-kin in a cancer hospital remain at the bedside because of the severity of the patient's condition; to provide psychological support; as a family tradition; because they did not believe that the patient was safe in the hospital; and because of shortage of healthcare professionals.

In Norway the government has launched a change in the next-of-kin policy including stronger involvement of next-of-kin in healthcare [9, 10]. The aim is to pay more attention to the interaction between the next-of-kin and the healthcare services to improve quality and safety of healthcare. A major concern is the lack of voluntary caregivers and recruitment of healthcare workers in the future. It is therefore crucial to acknowledge the next-of-kin expertise and explore their role [11].

Studies in other areas than cancer care such as transitional care [12, 13], elderly care [14, 15] and pediatrics [16, 17] have explored the influence of next-of-kin on quality and safety in healthcare. Jeffs and colleges results pointed out that the caregivers often become substitutes for adequate staffing and that future research should provide insight in how to best engage caregivers actively in care transitions. Storm and colleagues documented that quality was impaired by the lack of systematic information exchange between healthcare professionals and next-of-kin, and by the limited involvement and preparation of patients and next-of-kin for transitions across care levels within elderly care. Next-of-kin were bridging between the patient and healthcare professionals, they were patient advocates and supporters, and contributed to information brokering between the healthcare providers and the patient. Moreover, Rustad (2017) highlighted that next-of-kin provided important information about the patient's health, and supported the patient's self-care in the field of transitional care of the elderly [14]. Other previous studies have shown how family caregivers provide valuable information that improved safety for pediatric inpatients [16], and Davis and colleagues [18] highlighted predictors of healthcare professionals' attitudes towards next-of-kin involvement in quality improvement. In particular, a discouraging response from healthcare professionals decreased the support for next-of-kin involvement and had strong perceived negative effects on next-of-kin relationship with healthcare professionals [18]. Furthermore, some studies show that next-of-kin takes on several tasks they are unprepared to handle, often resulting in higher caregiver burden [19, 20].

Previous research indicates that there is limited knowledge about the healthcare professionals` and managers` perspective on involvement and the role of next-of-kin in cancer care. Moreover, there is a need to explore the division of work between healthcare services and next-of-kin to reduce burden, and to ensure a sustainable involvement in quality and safety improvement in hospital cancer care [1, 2].

Aim and research question

The aim of this study was to explore the influence of next-of-kin involvement on quality and safety improvement within cancer care in hospitals. This study also explored how managers and healthcare professionals understand the role of next-of-kin in cancer care, and what methods they use for next-of-kin involvement. The following research questions guided the study: How are next-of-kin involved in hospital cancer care? How do managers and healthcare professionals perceive challenges in next-of-kin involvement in cancer care?

By studying national policy documents and qualitative interviews with managers and healthcare professionals, this study contributes to a better understanding of the diversity and complexity of next-of-kin involvement in cancer care, and deepens the understanding of how the relationship between the patient, next-of-kin and healthcare services can improve the service quality and safety in this field.

Methods

Design and setting

This article is the first in a larger mixed-method convergent design study [21]. The purpose of a convergent design is to collect and analyze quantitative and qualitative data separately and merge the two in order to compare the results [21]. The study design in this article is a comparative multiple embedded case study of cancer departments in two Norwegian hospitals. A case is defined as a

hospital and the belonging cancer departments. The case is embedded, meaning that it includes several units of analysis (macro, meso, micro level) [22]. It includes managers at the meso level and healthcare personnel at the micro level. In addition, we use national policy documents and regulations to illustrate the macro level context. A case study research strategy is chosen because the phenomenon of next-of-kin involvement in hospitals` cancer care improvement is a complex process involving activities of daily operations of a hospital and cannot be explored in isolation from each other. Through the empirical material the purpose is to gain insight into the relation between next-of-kin interaction and its influence on quality and safety improvement. The two hospitals have been explored separately at the meso level (department managers) and at the micro level (healthcare professionals), within the respective cancer departments. The comparative design seeks the meaning of the similarities and differences in involvement and the challenges between the hospitals.

The case hospitals

Two cancer care departments at two university hospitals within one regional health authority (RHA) in Norway, constitute the studied cases. The two hospitals differ in size, employees and budget (Table 1), but are subject to the same national and regional policy documents.

Hospital A is the second-largest university hospital in the RHA. Its cancer department consists of two cancer care wards (40 beds), two outpatient clinics, and one radiation therapy unit. The outpatient clinics offer approximately 750 chemotherapy treatments per month. Hospital B is the largest university hospital in the RHA. This cancer department is the main regional cancer clinic. The cancer department at Hospital B consists of two inpatient wards, one outpatient clinic and one radiotherapy unit. Both departments have seen an increased amount of treatment and patient throughput in the last few years, and are consistently working to meet this challenge.

Data collection

The study applies several data sources. National policy document such as regulations, and reports to the parliament were collected and analyzed to explore the macro level context with focus on demands and expectations for next-of-kin involvement in general [10, 11] and, in cancer care [23] and patient safety [24]. At the meso level we conducted qualitative interviews with managers and, collected and analyzed hospital strategy documents. At the micro level we conducted qualitative semi-structured interviews with healthcare professionals in the two hospitals. Thirty-two semi-structured interviews were conducted over a four- month period (December 2015 to March 2016). All informants were recruited by their nearest manager using snowball sampling to identify additional informants. All managers and healthcare professionals belonging to the departments could be included as informants. Only one of the approached informants declined the invitation. Table 2 shows the total number of informants in Hospitals A and B.

All informants received information explaining the purpose of the study, methods, limitations, and what role they were expected to play and the possible outcome of the research. To ensure that the information was understood, we appointed a local coordinator in both hospitals to give information, and respond to any questions. All informants signed informed consent and we ensured to pinpoint in the startup session in each interview that it was voluntary to participate in the study, to avoid any ethical dilemma for the informants given that managers were involved in the recruitment.

Interview guides were developed based on the theoretical framework 'Organizing for Quality' [25]. Several theoretical models can be applied to guide quality improvement and patient safety work in hospitals [26]. Most of them mention organizational structure, leadership, culture, politics, work conditions, and learning to understand how hospitals organize for quality and patient safety [27]. The conceptualization of quality and safety of cancer care in this study supports Bate et al. (2008) including patient

Table 1 Contextual Description of the Two Cases

Context	Hospital A	Hospital B
Localization	Large city in Norway	Large city in Norway
Case hospital	University hospital Local hospital for 330.000 inhabitants Second largest regional cancer department	University hospital Local hospital for 420.000 inhabitants Largest regional cancer department
Employees	7500	12,000
Budget	6,8 billion NOK	10,8 billion NOK

Table 2 Total Number of Informants in the Two Hospitals

Hospital A		Hospital B	
Meso level (managers)		Meso level (managers)	
Consultant	1	Consultant	2
Nurse	2	Nurse	–
Oncology nurse	3	Oncology nurse	4
Quality manager	1	Quality manager	–
Micro level (healthcare professionals)		Micro level (healthcare professionals	
Consultant	2	Consultant	2
Nurse	4	Nurse	2
Oncology nurse	3	Oncology nurse	6
Total	16	Total	16

safety, clinical effectiveness and patient centeredness [25, 26]. The interview guides also included questions about conceptualization of quality and safety. Bate and colleagues focus on six challenges that need to be addressed in quality and safety improvement work. These are listed as topics in the interview guides. The six challenges are:

1. Structural – organizing, planning and coordinating quality efforts;
2. Political – addressing and dealing with the politics of change surrounding any quality improvement effort;
3. Cultural – giving 'quality' a shared, collective meaning, value and significance within the organization;
4. Educational – creating a learning process that supports improvement;
5. Emotional – engaging and mobilizing people by linking quality improvement efforts to inner sentiments and deeper commitments and beliefs;
6. Physical and technological – the designing of physical systems and technological infrastructure that supports and sustains quality efforts ([25], p.169).

The reason for applying the Organizing for Quality framework is based on a need for a system wide and multilevel perspective taking into account inner and outer context of the organization to help understand quality and safety processes [26]. The Organizing for Quality framework has been developed based on international studies of leading hospitals with success in quality improvement. Moreover, the framework has been applied in studies of Norwegian hospitals [28–30], in international studies [26, 31, 32] and as a foundation for a guide for hospital managers' work to improve quality and safety [31]. A systematic review of quality improvement models in healthcare from 2009 highlights that there is no single framework that stands out above the others. The key to success depends on the understanding of the interaction between the local context and the approach that is applied [33].

Analysis

Qualitative content analysis is one of many methods used for analyzing qualitative data. We have used directed content analysis inspired by Hsieh and Shannon (2005) [34] guided by the Organizing for Quality framework [25]. The goal was to determine the relationship between the six challenges described by Bate and colleagues and our research questions and to extend the empirical testing of the model. All members of the research team participated in the analysis using group consensus to strengthen validity of our findings [32]. IJB further developed the analysis with several iterations with all authors. Analysis began with the inductive approach (Fig. 1) to capture the essence of next-of-kin involvement in cancer care. Each member of the group did a three-step interpretive characterization of the two cases (Fig.1). Step 1: selecting units and levels of analysis; Step 2: open coding from plain text, defining categories and sub categories; Step 3: comparison of findings across cases and levels.

Findings of the inductive analysis are not the main focus of this article, but were an important part of the analytical validation of the results. Relevant policy documents were approached through close reading, searching for expectations related to involvement of next-of-kin.

In addition, the interview data was categorized according to the six challenges. In the deductive part of the analysis (Fig. 2) the research team met three times to discuss findings using the predetermined codes in the Organizing for Quality framework. The analysis followed a three-step model (Fig.2) within the six challenges in each case hospital, across organizational levels within each case, and across the two case hospitals:

Step 1: Selecting units and levels of analysis;

Step 2: Organizing data with predefined categories; discovery of meaningful units in plain text; condensing short summery of data from the informants; describing subcategories;

Step 3: Description of findings within the six challenges, across levels and cases.

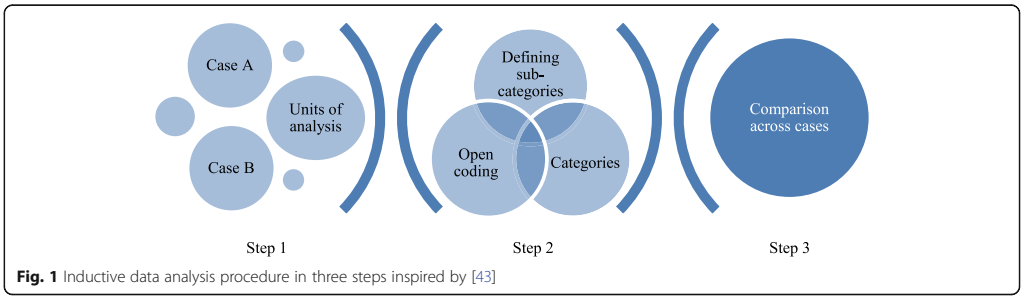

Fig. 1 Inductive data analysis procedure in three steps inspired by [43]

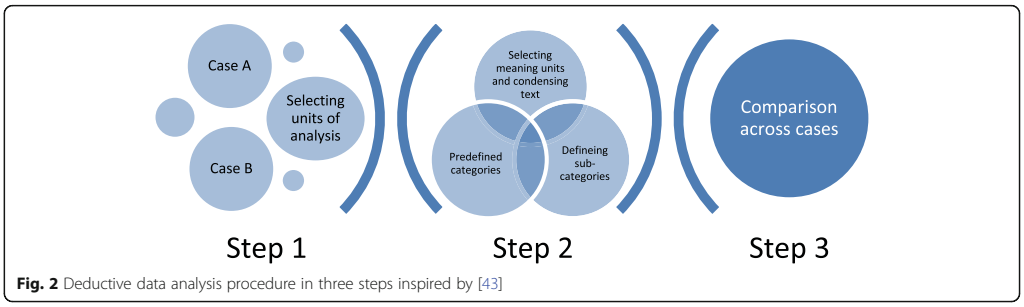

Fig. 2 Deductive data analysis procedure in three steps inspired by [43]

The deductive analysis using the Organizing for Quality Model corresponded well with our findings. There is always a risk that a predefined framework may bias the analysis. Our combination of an inductive and deductive approach contributed to prevent that the Organizing for Quality framework forced the analysis procedure in the deductive part. Using an analytical approach involving only a prior framework could imply omitting key findings emerging from results if they are not applicable in a predefined framework. In this study, we also argue that the six challenges in the Organizing for Quality framework are broad in scope and imply that the results contribute to give content to the challenges from a cancer context perspective. Relating the findings to the governing documents for specialized healthcare in Norway expands the perspective even more, as policy expressions deals with identical issues. The findings thus may be relevant for analysis and discussion irrespective of our chosen framework.

Results

The results are presented according to the six challenges in the result section. First, we start by presenting the national policy context. Then we present each challenge according to the Organizing for Quality framework with description of sub-categories. In the end of the result section we present a model for important areas of next-of-kin involvement that emerged by seeing the data material as a whole.

Context – National policy

The last 50 years the Norwegian healthcare sector has been characterized by an increasing public engagement in the provision of health care with generous benefits for the individual inhabitant when in need of healthcare [35]. The formal expectations for participation, economically and practically, by the family or members of the private network of a patient, are low.

There is no statutory obligation for next-of-kin to provide care, but according to the national strategy documents there is an expectation that it should be done either by love, citizenship or by duty. In the National Cancer Strategy in Norway [23], next-of-kin involvement is one of five objectives that are reported to improve safety. In 2013 the Norwegian board of Health Supervision conducted a risk analysis of cancer care [36]. One of top 16 patient safety hazards in this analysis is lack of involvement of patients and their next-of-kin. Results from the analysis of national policy documents show that there is a limited focus on the healthcare professional and managerial views on next-of-kin involvement, not only to support next-of-kin, but also to explore in what ways next-of-kin contributes to quality and safety in hospital cancer care.

Structural challenges

Lack of systematic approaches for next-of-kin involvement

In the two case hospitals, managers and healthcare professionals recognized next-of-kin as important supports in the cancer care trajectory. Interaction and next-of-kin collaboration was on the daily agenda. There was a holistic and respectful attitude to next-of-kin who are considered no less important than the patient, and natural collaboration partners. This was manifested in a written strategy in hospital A. In addition, hospital A adopted a value-based leadership which was known as 'Respect for all'. The latter seems successful in this hospital, and gave all employees a common vision, values and goal for treatment and care. Both hospitals' cancer departments valued next-of-kin involvement in different ways, but there was no systematic approach, or plan to operationalize a strategy for next-of-kin involvement. Managers and healthcare professionals at both sites insisted that a more structured way of guidance, such as a checklist in next-of-kin involvement, and a way of collecting information on next-of-kin experiences could improve the role of next-of-kin in improving care quality and safety. Managers and healthcare professionals at both sites were evocative of the national policy and the growing awareness of more next-of-kin involvement in care. Even if both hospitals had a strategy to enlist next-of-kin in treatment and care, there are few formal ways of doing so. Both managers and healthcare professionals claimed

that they depended on practical assistance and supervision of the patient from next-of-kin to improve quality and safety of cancer care.

Some methods and tools were identified in relation to collecting next-of-kin experiences. Among these were a questionnaire to next-of-kin, user surveys, and documentation of conversations with children. Both sites encouraged patients in summon letters to bring next-of-kin, and both managers and healthcare professionals often offered next-of-kin meetings or information phone calls. In addition, both hospitals offered unlimited phone hours, and both patient and next-of-kin could call in if they encountered difficulties after discharge.

> We are offering next-of-kin conversation or family meetings all the time if the patient wants to bring their next-of-kin. (Consultant)

Most methods focused on how to inform next-of-kin, but the methods did not have systematic means of guidance or educating next-of-kin in knowledge, attitude and practices relating to quality and safety.

Next-of-kin as quality and safety resources

The managers and healthcare professionals in both hospitals insisted that next-of-kin constitute important safety resources during treatment:

> Next-of-kin are very important during the course of treatment. For example, how safe it is for the patient to go home in neutropenic phase depends on whether they live alone or if they have careers who can act, help and support. Next-of-kin are a very important piece in addition to all emergency personnel in the municipalities, such as nurses, consultants, mobile palliative care team, nursing homes, or homecare services. (Consultant)

Results showed that healthcare professionals depended on collaboration with next-of-kin during patient discharge. Next-of-kin and especially family caregivers often had an important role that could not be replaced by professional healthcare workers. In addition, next-of-kin were considered an invaluable safety resource when the patient was frightened, anxious, restless, or if the facility was understaffed. Healthcare professionals also claimed that without next-of-kin present to help with a patient's feeding, observation or support it would be difficult to take proper care of them:

> If it wasn't for next-of-kin, the schedule would be disrupted. That could affect other patients with delayed medical care, food, and personal care. (Cancer nurse)

Lack of continuity reduces next-of-kin involvement

In both hospitals, managers and healthcare professionals argued that lack of experienced nurses and consultants were obstacles to next-of-kin involvement. This was described as the largest structural challenge to patient safety. In addition, it was more difficult to involve next-of-kin if the consultants did not know them or the patient. Next-of-kin have also complained about lack of continuity of care at both sites:

> We have received letters from both patients and next-of-kin who argue that it is tiring to deal with new faces every time they come to the clinic. They come every 14 days, and haven't seen the same consultant in the last 16 weeks. It is pretty bad! (Registrar)

Political challenge

Lack of interdisciplinary collaboration hampers next-of-kin involvement

Interdisciplinary collaboration is a success factor for next-of-kin involvement in both hospitals. However, the results showed problem with interdisciplinary collaboration, especially in Hospital A. Because of a lack of consultants, nurses felt obligated to take responsibility for tasks such as giving information about treatment options. The nurses expressed frustration over the lack of interdisciplinary arenas, while the consultants seldom acknowledge their own role in interdisciplinary meeting arenas:

> We had a patient who died in a lot of pain and we felt that we had failed in some ways, or that we were unable to help the way we wanted to, even if we spent a lot of time with the consultants in the palliative team. Then the nurses conducted a debrief and we were invited to sit in to talk about it. We don't have time to do so in the consultant group, I think was the idea then… (Registrar)

In Hospital B, registrars are rotated according to the day's resource needs. As a result, registrars often discharged patients they had never met before. In addition, registrars described that it was common to discharge up to ten patients a day, in addition to taking rounds. This workload made them unable to take the opportunity to learn from role models by joining consultants as they were giving information about treatment or prognosis to patients and next-of-kin.

Nurses and consultants in both sites were led by a manager that had no authority beyond their professional group. Result showed interdisciplinary differences in the conceptualization of quality and safety in cancer care services between the professional groups

on what the patient or next-of-kin should know before initiating treatment.

The difficult duty of confidentiality

Also important is maintaining confidentiality. Managers and healthcare professionals at both sites explained that next-of-kin should only be informed if the patient consents. At the same time, healthcare professionals claimed that next-of-kin in cancer care often have their own need for information, support, and guidance. Healthcare professionals spend a lot of time responding to requests from the next-of-kin. This activity was seldom documented, but it was important in terms of the close relationship between stakeholders following a cancer diagnosis. This was also an essential follow-up in terms of tasks delegated to the patient and next-of-kin when the patient is between treatments when confidential patient information was required.

Cultural challenge

Next-of-kin as an equal partner and a practical resource

In both hospitals, managers focused on building a collective culture with a holistic approach emphasizing that the whole family is affected when a person is diagnosed with cancer. The managers argued that they had to keep working on this, especially when new employees are hired, since the culture – for better and worse – is learned quickly:

> That has something to do with safety. That you dare to stand in to do difficult and tough tasks. To answer questions and tasks that comes from next-of-kin. We have had next-of-kin who have sat by the bed for several days. When we ask them why, they respond that it is because they don't dare to leave the patient. They have seen the pace we have. (Cancer nurse)

When the nurses were asked what they ask next-of-kin to do, they responded that next-of-kin are not given medical tasks. The nurses seemed reluctant to talk about this:

> We can probably not say that we give them (next-of-kin) medical tasks in a way, but they help with safety, care, showers and other such things. Not so much the medical care really, but they might help with giving medications. Pills. (Cancer nurse)

Healthcare professionals described the balance between involving and using next-of-kin as a practical resource as a 'grey zone'. Nurses asked next-of-kin to perform some tasks because they wanted to involve them, but mostly because the nurses did not have the time or staffing. The results indicate that healthcare professionals depend on next-of-kin in care provision due to understaffing and peak problems.

Educational challenge

Limited systematic next-of-kin education

The interviews with healthcare professionals in Hospital A revealed that there is literally no room for professional updates for managers or healthcare professionals in the nursing group.

Quality champions in the department must work hard to get the management to prioritize academic and research projects. The managers struggled with patient overload and shift coverage with experienced personnel.

The cancer department at Hospital A provided education to breast cancer patients, but they did not invite next-of-kin. No formal education was offered to next-of-kin and next-of-kin was not a topic in the newly designed courses. In Hospital B we found a more stable workgroup of cancer nurses. More attention was paid to learning and education, but as in Hospital A there was no formal education for the next-of-kin. Both hospitals seldom used next-of-kin experiences in courses or education, but they often discussed ethical aspects in patient care and individual needs in the ward on a daily basis. The registrars in Hospital A were pleased with the education activities. They reported that consultants were good role models and accessible, and there was room for professional updates. The registrars in Hospital B were seldom included in difficult patient meeting as part of their professional training, and did not experience increased professional responsibility in parallel with increased professional experience:

> You feel that you are stagnating a bit. You have to stay so long on the little less challenging operating level. You dream of more treatment responsibilities and having your own patients. (Registrar)

The emotional challenge

Unspoken expectations of next-of-kin performance and emotional stress

In this category, the next-of-kin role is described as an emotional difficulty from the nurses' perspective. In both hospitals, next-of-kin were invited to accompany the patient to treatment or information meetings. However, the result showed that the nurses were unclear about the role of next-of-kin. Healthcare professionals expect next-of-kin to be active and participating, but do not articulate this to them:

> It is not said out loud, but basically you have expectations once they (next-of-kin) are there. (…) That they try to be active in their role, and not just sit passively by the patient and expect something of us. (Cancer nurse)

In the interviews, there are several examples of next-of-kin sitting at bedside for days due to concerns with medication or staffing. This was difficult for healthcare professionals to resolve. When nurses and consultants receive critical feedback they often took it personally, even if the criticism was directed at the system.

Managers, especially in Hospital A, reported spending a lot of time handling emotional stress among staff. The healthcare professionals experienced emotional stress because they set the priorities, and even if done correctly, it could still feel wrong.

Physical and technological challenge

Location and infrastructure affect possibilities for next-of-kin involvement

Both hospitals had too many patients for their capacity. Healthcare professionals sometimes need to ask next-of-kin to leave the room or to be quiet, because of overcrowded rooms.

In the interviews in Hospital B, informants noted that having too many next-of-kin in small rooms could increase emergency risk and complicate an evacuation. Next-of-kin involvement in general was easier in single room wards. In Hospital B we found two inpatient wards that had different designs. One ward was new and designed with single rooms and two double rooms, with additional bathrooms. A room was reserved for next-of-kin to nap or take breaks. In the other ward, we found rooms designed for four patients with one small bathroom in the hallway. The healthcare professionals claimed that next-of-kin involvement was much easier in the new ward than in the hospital room designed for four patients:

> It is too little space. It can affect patient safety. (…). It is too many patients and next-of-kin in one room. There is not enough equipment. You need to use a lot of time to look for equipment and to find a place. We have to take what we find, because there is not enough room for everybody. (Manager)

The results also showed that the documentary system did not include designated areas for documentation of information or correspondence with next-of-kin. Healthcare professionals often spent a lot of time figuring out what information next-of-kin had received, their resources, the patient's network, and how next-of-kin were involved in the cancer care process.

Areas of next-of-kin involvement in hospitals

Healthcare professionals and managers in this study identified nine areas in which next-of-kin are involved in improving quality and safety (Fig. 3: Model 1). These nine areas were common across the two hospitals, organizational levels and professions within the cancer departments. Next-of-kin were involved in terms of having key information about the patient, for motivating patients during treatment and taking on responsibilities and work tasks related to nutrition, medication, and rehabilitation. Also in transitional care, healthcare professionals depended on involvement of next-of-kin to ensure sound transfer between care levels. During both hospital stay and between care levels next-of-kin were involved in care provision as resources in observation of patients, in parts of daily care, and particularly during palliative and terminal care.

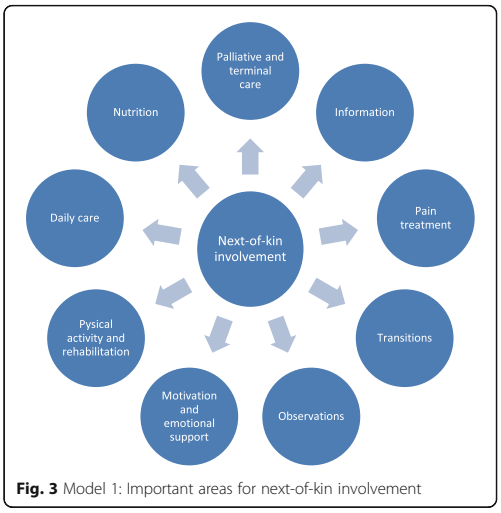

Fig. 3 Model 1: Important areas for next-of-kin involvement

Model 1: Important areas for next-of-kin involvement

Some of these areas were described as more natural for next-of-kin to be involved in (information, motivation and palliative/terminal care) considering the close relationship with the patient. But healthcare professionals describe that there is a fine line between being involved for the patients and next-of-kins` best, or being involved because of capacity problems in the department (pain treatment, observation, daily care). Next-of-kin involvement is described as a sensitive area that requires more attention and these nine areas, identified by healthcare professionals and managers, can be used by the hospital cancer care to develop a more thorough understanding of next-of-kin's role and contribution.

Discussion

Similarities and differences between hospitals

This study of managers' and healthcare professionals' views and experiences with next-of-kin involvement in cancer care, substantiate a link between next-of-kin involvement,

clinical safety, quality improvement, and patient outcome. The role of user involvement to promote better patient outcomes are highlighted by the Institute of Medicine [6] and involvement is also highlighted as a key resource in quality and safety improvement in national government documents [9, 10]. At the meso level, managers at both sites commented on the national government's change in the next-of-kin policy towards stronger and more involvement. However, there was some confusion over what this involvement should consist of. This was because managers and healthcare professionals claimed that in cancer care there is already a close interaction among the patient, healthcare professionals and next-of-kin. More surprisingly, our study showed that the close interaction with next-of-kin did not follow a structured approach or method of involvement. Consistent with findings in other studies [1, 2], healthcare services and cancer care lack knowledge about methods for involvement. Moreover, this study showed that healthcare professionals at both hospitals lacked knowledge and awareness of next-of-kin role and contribution to quality and patient safety. This calls for a change in national next-of-kin policy. In cancer care, attention should not only be targeted to more or stronger involvement but rather on how healthcare professionals can customize next-of-kin support for each patient. Cancer care departments could also benefit from a more tailored next-of-kin involvement with additional training in e.g. pain management or nutrition (Fig. 3: model 1). This can contribute to increased awareness of the responsibility and work done by the next-of-kin, not only for the patient, but also for the healthcare services.

Findings in this study show that the cancer care provision depends on next-of-kin involvement and collaboration as patients move across service levels. This is not only because of shortage of staff or personnel, but because next-of-kin are sources of valuable knowledge and make a contribution to the patient's ability to handle and recover from cancer treatment. Next-of-kin cannot be replaced by other stakeholders, and our study parallels other studies showing that next-of-kin takes on tasks for which they are unprepared [19, 20]. Other studies of transitional care equals to ours in terms of the important role of next-of-kin as information carrier [15]. Despite the close interaction between healthcare professionals and next-of-kin we found in the study, next-of-kin were seldom included as an equal part of the care team. Similar results from a Norway have been described by Wiig and colleagues in maternity care [37].

In addition, healthcare professionals and managers in our study emphasized that the next-of-kin carry a heavy burden that can affect their health, work, and family life [5, 38]. Benefits of a more structured approach to next-of-kin involvement in hospital cancer care such as a guide can be twofold. First, it may lighten the next-of-kin's burden by dividing tasks between healthcare professionals and other stakeholders. Second, it may increase the awareness of next-of-kin's role in improving the quality and safety of cancer care.

Both hospitals had a positive emotional and cultural environment with strong commitment to patient and next-of-kin. Collective values, interdisciplinary collaboration and commitment acknowledged the role of next-of-kin in the cancer care trajectory. Still, this is not enough to involve next-of-kin appropriately. Despite internally motivated clinical engagement, findings showed that lack of continuity, frustration with interdisciplinary collaboration, external demands and critical feedback from next-of-kin were emotionally stressful for the healthcare professionals. It is important to ask if this emotional stress influences healthcare professionals' clinical performance in cancer care. Some studies have argued that healthcare professionals' feelings can compromise patient safety [39, 40], while other studies indicate that oncology nurses' vigilance can affect patient safety, and the appropriate involvement of next-of-kin may allow nurses to be more vigilant [41] .

The physical and technological challenge stood out as the main significant difference between the two hospitals. In Hospital B we found that workplace conditions (e.g., four-bed rooms and limited space) which both managers and healthcare professionals experienced reducing their abilities to involve next-of-kin in cancer care. These findings are consistent with Bate et al.'s study [25] of the functional physical working environment as a foundation for quality improvement work.

This study has highlighted nine important areas for next-of-kin involvement in hospital cancer care (Fig. 3: model 1). This new knowledge might be helpful for managers and healthcare professionals to develop, explore, and create interventions or methods related to each of the nine areas. Moreover, the nine areas can stimulate a discussion at the macro level about what stronger involvement of next-of-kin should look like. Based on our findings, the discussion should be directed to more structured approaches for next-of-kin involvement. In addition, the next-of-kin policy in Norway does not make a distinction between being next-of-kin in cancer care or other diagnostic fields [9–11]. Our study indicates that there may be a significant difference. Next-of-kin involvement in cancer care could be treated as a separate group in terms of developing interventions, methods and guidance for involvement in quality and safety improvement related to the nine areas identified in our study (Fig. 3: Model 1). Even though the results stem from cancer care, the nine areas in Fig. 3: Model 1 might be transferrable to other diagnostic fields, especially in the Nordic countries, due to similarities in organizing of healthcare systems [42].

Organizing next-of-kin involvement in cancer care – Suggestion for framework development

Our findings bring a new perspective to next-of-kin's role in and contribution to the cancer care trajectory. They demonstrate the complexity of hospital organizational context and how it affects healthcare professionals and managers in their daily meetings with next-of-kin. The Organizing for Quality framework was applied when analyzing the qualitative data according to the six common challenges [25]. Anchored in our findings, we suggest further development of the framework shown in Fig. 4: Model 2. We specify areas of key importance for next-of-kin involvement under each challenge to elaborate and specify content to the six challenges. By doing this, we simplify application of the framework in a stakeholder perspective in research and everyday clinical practice [26, 30]. Our development is relevant for future predictions and prospects for governments, the research field, managers and healthcare professionals to strengthen the dimension of next-of-kin involvement in improvement of hospital cancer care. The six challenges were common across the two case hospitals, but should be tested by managers and healthcare professionals in a larger sample of hospital cancer care settings in Norway and an international context [25, 32].

Model 2: Revised framework model inspired by [25]

We suggest that the structural challenge is to build competence on what a more structured approach (guidance and methods) can contribute with for making the cancer care journey better and safer for the patient. The political- and cultural challenge needs to include organizational acknowledgement of the role next-of-kin holds in quality and safety work and acknowledge next-of-kin as a potential resource for both the patient and healthcare services. The educational challenge, needs to create educational activities to support the next-of-kin role, resources, and ability to master and adapt to the cancer journey. The emotional challenge is to strike a balance between next-of-kin involvement and next-of-kin burden. Our study shows that no cancer journey is free of burdens, but there could be a mutual obligation to ensure that the division of work is balanced among all stakeholders, including next-of-kin. With regards to the physical and technological challenge, there is a need to ensure that locations and workplace conditions support next-of-kin involvement.

Limitations

The two hospitals were selected because they have the same external context, are similar in structure, location and belong to the same RHA. Based on the sample, we cannot illuminate variations, for instance if we selected hospitals based on good or poor performance, or not within the same RHA. We explored only two hospitals. A larger sample could have generated different findings. This study did not include next-of-kin. Their perspective is covered in another stage of the project. This articles` main focus was a manager and healthcare professional viewpoint. However, with the limitations in mind, we have described and derived meaningful insight and a new perspective on the next-of-kin role in quality and safety improvement with a multilevel approach (macro, meso, micro). We are confident that this approach will

Fig. 4 Model 2: Revised framework model inspired by [25]

contribute to understanding the next-of-kin's role in improving quality and safety in cancer care.

Conclusion

In this study, we have explored the influence of next-of-kin involvement in quality and safety improvement within cancer care in two hospitals. The study shows that next-of-kin holds an important safety dimension in patient-centred care [6] and demonstrates a close interaction and collaboration among patient, next-of-kin, and healthcare professionals in cancer care. However, there were no systematic approaches, strategies and plans for next-of-kin involvement. The perceived challenges that healthcare professionals described were closely connected to hospital context, workplace conditions and awareness of next-of-kin involvement as a resource for quality and safety improvement. Based on descriptions across the two case hospitals, care levels, and professions, we identified nine areas (Fig. 3: Model 1), where next-of-kin are important stakeholders in improving quality and safety (nutrition, palliative and terminal care, information, pain treatment, transitions, observations, motivation and emotional support, physical activity and rehabilitation, and daily care). Next-of-kin were silent external partners in the medical team around the patient that often had significant responsibilities. Their knowledge was used by the healthcare professionals, but they were seldom acknowledged in the same way as the other stakeholders around the patient with regards to education, guidance, or other systematic means of involvement.

Future research steps and clinical implication for next-of-kin involvement could benefit from using the suggested revision of the Organizing for Quality framework (Fig. 4: Model 2) to develop organizational procedures or as a basis for evaluating how different healthcare organizations practice next-of-kin involvement. Additional studies should include next-of-kin experiences and perspectives on how they would like to be involved in improving quality and safety in cancer care. Finally, future research should investigate how a more structured approach to next-of-kin involvement in cancer care, such as a guide or checklist, influence patient outcome and reduction in next-of-kin burden.

Abbreviation

RHA: Regional Health Authority

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Availability of data and materials

The dataset used and analyzed during this study are available from the corresponding author on reasonable request.

Authors' contributions

IJB have contributed to the study design, most of the data collection, within and cross case analysis and interpretation of data, and have prepared and revised the manuscript. SW contributed to the study design, parts of the data collection, within and cross case analysis and interpretation of data, and contributed in preparing and revising the manuscript. GSB contributed in the group consensus approach with analysis and interpretation of data, and with significant comments to the manuscript drafts and revision. BG contributed in the group consensus approach with analysis and interpretation of data, and has commented on manuscript drafts and revision. All authors have approved the final manuscript.

Ethics approval and consent to participate

The study is approved by the Regional Committee for Medicine and Health Research Ethics in Norway (2015/1488). Participation in the study is based on voluntary recruitment and written informed consent. The project has also been approved by the data protection officers at the two case hospitals.

Competing interests

The authors declare that they have no competing interests.

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Paper II

OPEN

Resilience From a Stakeholder Perspective: The Role of Next of Kin in Cancer Care

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Objective: The aim of this article was to provide new knowledge on how next of kin are co-creators of resilient performance, as seen from the viewpoint of the healthcare personnel and managers. The following research question guided the study: How are next of kin involved in shaping resilience within cancer care in hospitals?

Methods: The design of the study is a case study of cancer departments in two Norwegian hospitals. Data collection included a total of 32 qualitative semistructured interviews at two organizational levels (managers and staff). The data were analyzed by ways of a directed content analysis according to Hollnagel's Resilience in Health Care framework of resilience potentials (anticipate, monitor, respond, learn).

Results: Next of kin are involved in creating and maintaining resilience in cancer care by different kind of activities and in-depth insight into the patient's condition, which strengthen all resilience potentials of responding, anticipation, monitoring, and learning. We have identified nine areas in which next of kin are co-creators in shaping resilience. Next of kin are important stakeholders, both as safety experts and as safety resources, helping healthcare professionals provide quality and safety in the patient care process under difficult conditions. Next of kin's knowledge of the patient's history, their observation of the patient over time within the hospital, at home, and across care transitions are key elements of their contribution.

Conclusions: Next of kin complement healthcare professionals in all four potentials for resilient performance. The study suggests that the Resilience in Health Care framework takes into account the role of next of kin, as a stakeholder potential, because this has not previously been sufficiently considered.

Key Words: resilience, hospital, cancer care, stakeholder, next of kin

Abbreviations: RHC = Resilient Health Care, WAD = Work-As-Done, WAI = Work-As-Imagined

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Patients with cancer experience adverse events more frequently than other hospital patients.[1] Safety in healthcare is often described as a moving target and that numerous stakeholders are involved in keeping patients safe.[2] Families and next of kin are described as important safety experts but are rarely included in the patient's medical team.[3–7] Despite the increasing focus on patient safety in the last decade,[8,9] studies have neglected these stakeholders.[4,10–13]

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Resilience in Healthcare

Resilience theory has entered the safety research agenda in healthcare organizations.[14–17] Resilience theory also focuses on how healthcare is provided under various conditions and how healthcare personnel adapt their practice. In this field, stakeholders are considered important actors; however, the stakeholder perspective is underexplored in the literature.[14,18] The latter indicate a twofold need: (1) to understand the next of kin role in healthcare organizations and (2) to explore the stakeholder phenomenon in resilience.[19,20]

There are numerous definitions of resilience in different research traditions.[21] In this article, we use the definition of Resilient Health Care (RHC) by Hollnagel et al[15]: "Resilient health care can be defined as a health care system's ability to adjust its functioning prior to, during, or following changes and disturbances, so that it can sustain required performance under both expected and unexpected conditions"[14 pp: XXV]. Hollnagel and colleagues[14,22,23] argue that human and organizational performance depends on the following four potentials that are essential for resilient performance:

1. The potential to respond: this means to know what to do and being able to adjust and respond to expected and unexpected conditions and disturbances, by activating prepared actions or adapt mode of functioning. The ability to respond depends on the preparedness to monitor and the right resources.[14,22,23]
2. The potential to monitor: this means knowing what to look for and being able to monitor both the organizational environment but also the operating environment, in terms of what affects or could affect the organization's performance. Monitor is the foundation for the ability to respond.[14,22,23]
3. The potential to learn: this means knowing what has happened and the ability to learn from experiences, including success and failure, and making sense of experiences over time. Learning is the foundation for the ability to respond, monitor, and anticipate.[14,22,23]
4. The potential to anticipate: this means knowing what to expect or being able to prepare for what to expect[14,22,23] of, e.g., future development, options, threats, risks, potential disruptions, and changes in work conditions or operating conditions.

These four potentials are necessary for understanding resilience in healthcare.[16] However, there is also a need to develop a more detailed knowledge of the content of the potentials in everyday clinical settings, which will be addressed in this article.

Next of Kin Policy in Norway

Norwegian healthcare is a public responsibility, and the formal expectations of family members or next of kin are low.[24] The government has changed its next-of-kin policy to highlight them as important stakeholders for the patient and the healthcare system and should therefore be more involved.[25] The aims are to give attention to the relationship among the patient, next of kin, and the healthcare services to improve the quality and safety of healthcare and strengthen user involvement, including involvement of next of kin, as a legal right.[26]

Aim and Research Question

The aims of this article are to explore the stakeholder perspective in cancer care and to generate new knowledge on how next of kin in Norwegian hospitals within the cancer care field can be co-creators of resilience in healthcare services, from the viewpoint of healthcare professionals and managers. The article explores how next of kin to patients with cancer contribute to create and maintain resilience in the chain of service provision.

The following research question guides the study: How are next of kin involved in shaping resilience within cancer care in hospitals?

The article takes the perspective of healthcare professionals and managers by revealing the awareness of the next-of-kin role in resilience at the operational level.

METHODS

Design and Study Settings

The design is a case study[27] of two large Norwegian hospitals. The hospitals are within the same regional health authority and subject to the same national and regional policy documents. The cases have been explored at two organizational levels: clinical department managers at the meso level and multidisciplinary healthcare professionals at the micro level.

Data Collection

Thirty-two qualitative semistructured interviews were conducted in the two case hospitals for a 4-month period (December 2015–March 2016). Table 1 shows an overview of data collection for this study.

The interviews were based on an interview guide inspired by Bate et al.[28] The questions were related to the structure, politics, culture, education, emotions, and physical and technological challenges of the organizing for next of kin involvement. In addition, questions covered next-of-kin role and contribution to quality and patient safety, e.g., "What is the role of next of kin to cancer patient in your work place? How do next of kin contribute to quality and safety of cancer patients?; How do healthcare professionals consider next of kin who are speaking up about quality or patient safety concerns?" The data collection is described more closely by Bergerød et al (2018).[6]

Ethics Approval and Consent to Participate

The study has been acknowledged by the Regional Committee for Medicine and Health Research Ethics in Norway (2015/1488). Participation is based on voluntary recruitment and written informed consent. In accordance with the requirements in the Personal Data Act, the project has been approved by the data protection officers at the two hospitals.

Analysis

All interviews were transcribed and the data were analyzed by a directed content analysis according to Hsieh and Shannon (2005)[29] guided by the RHC framework for resilient performance,[15,22] and the four potentials of respond, monitor, anticipate, and learn. Through our analysis, we developed identified resilience-shaping factors by analysis of the content in cancer care focusing on the role of next of kin as stakeholders. All authors read the transcribed interviews and contributed to the analysis. I.J.B. led the analytical work in discussions with G.S.B. and S.W. on how to categorize the data according to the four resilience potentials.

RESULTS

The results are presented according to the RHC framework and the four potentials for resilient performance.[15,16,22] Under each heading, we include mechanisms where next of kin contribute as resilience-shaping factors.

The Potential to Respond

Next of Kin's Ability to Observe Guides Care Decisions-Makers' Response

The health professionals in this study highlight next of kin as important stakeholders in helping them respond more quickly to change in patient condition, because of their observations. Results show that healthcare professionals do not always know if it is safe for the patient to go home between treatments. If the patients, e.g., live with their next of kin, they are more likely to be discharged because they have someone who can observe and respond in case of adverse events such as fever, bleeding, or other discomfort related to the treatment or illness. In these situations, next of kin are often referred to as equally or more important than other healthcare personnel in the municipality.

> *We discharge many patients who are very ill. For example, when there is a compression fracture in the column, we are afraid of threatening cross-sectional lesion or patients on chemotherapy that have to come to the hospital rapidly if they experience fever. They [next of kin] are widely utilized. It is very often that we miss it when next of kin are not present. (Consultant, hospital A)*

Next of kin often guide healthcare professionals in making care decisions. The findings show that observations from next of kin

TABLE 1. Overview of the Data Collection

Hospital A		Hospital B	
Meso level (managers)		Meso level (managers)	
Consultant	1	Consultant	2
Nurse	2	Nurse	—
Oncology nurse	3	Oncology nurse	4
Quality manager	1	Quality manager	—
Micro level (healthcare professionals)		Micro level (healthcare professionals)	
Consultant	2	Consultant	2
Nurse	4	Nurse	2
Oncology nurse	3	Oncology nurse	6
Total	16	Total	16

provide important knowledge and insight into how capable the patients are of handling the burden and adverse effects of treatment. When next of kin are involved, they often give healthcare professionals important information that can help understand the patient's condition. This information can be crucial for deciding further treatment or changing the care plan.

> *Lastly, I participated in rounds with a preterminal pa tient,who, even though she was awake and perceived as being clear and oriented, did not make sense of pain. She had a serious infection and pneumonia, and we tried to ask her if there was a change in the condition concerning cough or breathing. Then the husband could tell us that her breathing had become worse and that he felt she was breathing more heavily. This happens quite often. (Consultant, hospital A)*

Dependency of Next of Kin in Daily Care to Respond Quickly

Managers and healthcare professionals claim to depend on next of kin to give the patient safe and high-quality care. Next of kin perform important care tasks, e.g., if the patient needs to be fed or is uncomfortable. These tasks often require the staff to be with the patient for a long time. On shifts with low staffing, next of kin are often the "pieces of the puzzle" that help managers and staff complete all tasks required of them by internal and external stakeholders (e.g., other patients, management, wards, or colleagues). This next of kin empowerment enables the staff to respond more quickly to patients who do not have their next of kin at bedside.

The Potential to Monitor

Next of Kin Watch Over Medication and Nutrition in Patient Care

The next of kin are assigned daily tasks either by the patient or healthcare professionals related to monitoring the patient's medication for pain treatment, nutrition, and daily care.

> *They [next of kin] often help to transport the patient, follow the patient to take blood samples, check the medical list, and also ensure that the patient takes the medication at the right time, especially if the patient doesn't want homecare. They inject medications, measure temperature and contact the hospital if the patient experiences fever. They [next of kin] have a huge sense of responsibility he patient and are resource persons for the patient, us (hospital), and the municipalities. (Nurse, hospital A)*

Healthcare professionals describe how next of kin have in-depth knowledge about the patient including how he/she was before the cancer diagnosis. For example, if the patient had poor appetite, a next of kin will sometimes know better than a nurse what the patient would eat and is often a good resource in encouraging the patient to eat.

Next of Kin Oversee Patient Activity Level

Physical activity and rehabilitation before new treatment are another area where next of kin's ability to monitor the patient is highlighted. Next of kin are often considered to have the capacity and motivation to contribute something extra during patient visits. Healthcare professionals often suggest that next of kin can help the patient with daily activities or physical activity by, e.g., taking the patient for a walk. In the hospital, this should be voluntary, but when the patient is at home between treatments, the expectation of next of kin's contribution to daily care is more explicit.

Watching Patient Signals in Palliative and Terminal Care

Healthcare professionals note that next of kin often are important partners in monitoring palliative and terminal care. Next of kin's involvement seemed to be more obvious and legitimized in this area. Healthcare professionals often work in close collaboration with next of kin in terminal care. In this stage, healthcare professionals learn and inform next of kin what to look for in the patient's condition, how to care for the patient by, e.g., moisturizing the mouth or observing if the patients are in pain or discomfort. The next of kin's perceptions are considered when the patient's condition changes. Healthcare professionals and next of kin often have different views and expectations of what is in the patient's best interest. This disparity is most pronounced in what poses a potential risk to the patient. A lack of involvement of next of kin perceptions and expertise may result in an adverse outcome:

> *Then one evening the patient became very ill. There was a lot of medication and people all over the place. The problem was not lack of resources. The next of kin perceived that the patient was dying, and she probably was. This was not conveyed. There was so much turmoil that they [next of kin] felt overlooked. They went home. That night the patient died alone. (Consultant, hospital B)*

The Potential to Learn

Key Role for Safe Transitions Across Care Levels

As we saw in the next of kin potential to monitor, the potential to learn highlights next of kin's experiences and perceptions of the patient condition as important features of the hospital's ability to provide safe cancer care. Results show that the next of kin have a key role that cannot be fully replaced by other stakeholders or hospital staff in terms of making sense of experiences for safe transitions and incorporating informal learning processes between service levels. Next of kin contribute to healthcare services by helping the patient between home and hospital and with transfers between care levels within the hospital. Next of kin often hold and share important experiences that help healthcare professionals in improving their services by learning more about the patient's previous condition and history. Healthcare professionals describe the importance of continuity of care among healthcare professionals for building a close and collaborative relationship among all stakeholders to adjust and learn from next of kin's perceptions and experiences.

> *I think it's an assurance for next of kin that they meet the same nurses. Next of kin seem to report more of the actual patient condition when they meet the same nurses. (Quality manager, hospital B)*

In addition, next of kin often take a questioning role and thereby contribute to stronger vigilance among the healthcare professionals about issues such as medications and injection rates. Results indicate that healthcare professionals may detect failures sooner and avoid adverse events because of reminders from next of kin.

The Potential to Anticipate

Next of Kin Are Foreseeing Possible Deteriorations and Treatment Consequences

In this study, the potential to anticipate is highlighted as an area for growth and more systematic investigation. This study finds two important mechanisms that are essential for the potential for anticipating: (1) how healthcare professionals involve next of

kin to understand the possible consequences of treatment and care and (2) how healthcare professionals enable next of kin to foresee and handle adverse events and possible deterioration in the patient's health.

In the two hospitals, we found no systematic next-of-kin involvement or special training for next of kin even if they were performing tasks requiring special training and skills:

> *A next of kin approached me today and said, "We feel so alone in this. We control things that we cannot really do. We provide injections and do things we do not have education to do." (Consultant hospital B)*

Healthcare professionals describe often asking the next of kin to observe the patient over time, report changes in the patient's condition, assist the patient with daily care, bring food or drinks to the patient, feed the patient, and share information that can prevent adverse events and enhance the quality of care. Next of kin are often a unique and invaluable resource for quality and safety of cancer care. One of the most appreciated features of next of kin involvement is the ability to motivate the patient and to share information about the patient.

> *…the most important contribution from next of kin is the dissemination of information at the doctor's or nurse consultations. […] Next of kin have a greater ability to understand because they are there for the patient while the patient has more than enough with himself. (Manager, hospital B)*

The division of work seems to come naturally because of the close relationship between the next of kin and the patient, but it also causes challenges. In both hospitals, there was confusion about what the next of kin could be asked to do and what role the next of kin should have in hospital cancer care. This is in contrast to the finding that the next of kin have a coordinating function in cancer care.

This result indicates that the hospital cancer care would benefit from a more systematic approach to next-of-kin involvement, enabling them to act promptly in light of the possible consequences of treatment and care by teaching them what to expect. Next-of-kin involvement may also strengthen the reflective processes around the patient by introducing viewpoints and observations that are not readily accessible to the health personnel, e.g., what the patient's life was like before the cancer diagnosis.

DISCUSSION

Theory Development: Next of Kin Performance in Resilience

Hollnagel[22] argues that resilience performance in organizations can be understood through the four resilience potentials. Moreover, Hollnagel[22] argues that if the organization lacks these potentials, it will be incapable of resilient performance. Our findings indicate that next of kin constitute a new potential that supports the other four. Weakness in monitoring, learning, anticipating, and responding in a clinical setting can be prevented by the use of next-of-kin information, observation, and task performance, as shown in this study. This depends on collaboration between the next of kin or other key stakeholders around the patient, implying that a stakeholder analysis early in the cancer trajectory could make it easier for healthcare professionals and managers to take advantage of their information and skills in patient care.

This study brings a new aspect to the operationalization of the resilience potentials in hospital cancer care by describing healthcare professionals' and managers' view on next-of-kin role in the trajectory of cancer care. This study offers new knowledge on how next of kin are co-creators of resilience. The resilience healthcare theory and the potentials for resilient performance have been criticized for lacking descriptions and clarity of conceptual links between theory and everyday practice in complex systems.[30–32] This study contributes to a better understanding of resilience in a stakeholder perspective, by bringing context-specific and clinically relevant content into the four potentials for resilient performance in hospital cancer care.[22] In our view, these potentials need further operationalization. The RHC theory could benefit from more studies to refine key constructs in the potentials and position resilience into everyday practice across organizational levels. This may give a deeper understanding of different contextual settings and a foundation for interventions in healthcare organizations.

The Stakeholder Potential: A Key Piece of the Puzzle

In both cancer care departments, we found a close, interactive, and collaborative relationship among healthcare professionals, the patient, and next of kin. The next of kin held a key role as safety experts. Healthcare professionals describe next of kin as important stakeholders contributing to patient safety by, e.g., helping them respond more quickly to changes in the patient's condition and by sharing important information in decision-making to ensure the best quality of treatment.

Next of kin complement healthcare professionals in all four potentials for resilient performance by their unique insights and responses. The close relationship seems to be a prerequisite for healthcare professionals' adaptations in patient care during disruptions and challenges. The healthcare professionals in our study identified nine areas in which next of kin are important resources in improving quality and safety. Similar to O'Hara et al[18] talking about the family as part of scaffolding the system and the study by Fyland et al[33] showing that patients are an underrecognized resource in system resilience, our study shows that next of kin are a key resource in nine areas of system resilience in the cancer trajectory. Figure 1 gives an overview of next of kin's contribution to the four potentials in hospital cancer care. These nine areas were common across the two hospitals' cancer care departments.

This study offers several descriptions of healthcare professionals' dependence on next of kin as a practical resource with unique insight in cancer care.[6] At the most difficult times, healthcare professionals often used next of kin to perform some tasks. In these situations, next of kin functioned as safety resources that compensated for the hospital staff's shortfalls, e.g., by calming an anxious patient, feeding, noting changes, or providing daily care. When the organization lacked capacity, next of kin became the piece of the puzzle that helped healthcare professionals provide sound care despite heavy workload, understaffing, or other potential threats to patient safety.

At first glance, this seems to be a rational decision when there is a high risk of adverse events and it is difficult for healthcare professionals to provide sound patient care. On the one hand, this could be taken as a success story for resilient performance. On the other hand, taking into account studies highlighting the many burdens next-of-kin shoulder,[12,34] it is important to understand the potential burdens for stakeholders. Failure in communication and lack of involvement of next of kin are among the top 16 patient safety hazards in Norwegian cancer care.[35]

Although the structure depicted in Figure 1 shows similarities with the traditional layout of Deming's circle, it should not be apprehended in a mechanical way.[36] From a clinical perspective,

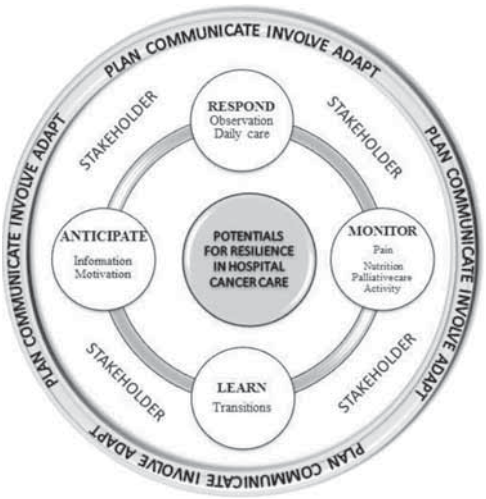

FIGURE 1. Next of kin contribution in hospital cancer care.

monitoring often precedes responding. Therefore, it seems rational to describe the elements as potentials, not as processes. A possible fifth potential, allowing for active involvement of patients and next of kin, could therefore be to expand the model to include a potential for stakeholder involvement and collaboration. However, there is a need to plan, communicate, and make adjustments in the involvement process, as depicted in Figure 1. This will apply to all the four potentials and could possibly form the basis as a prerequisite for other contexts. Hollangel[22] has asked whether there is need for additional potentials such as planning, communication, and adaptation. Our suggestion of stakeholder involvement as a potential may not meet Hollnagel's criterion of potentials as functions in organizations,[22] but a stronger understanding of the stakeholder perspective and a more systematic analysis and involvement of the patient (e.g., the study by Fylan et al[33]) and the stakeholders will strengthen the possibilities of operationalizing resilience in different clinical settings.[18]

The findings in this study indicate a divergence between how healthcare professionals use next of kin as a practical resource in practice and their ideal involvement with next of kin. Ideally, next of kin should participate in patient care on their own terms and not because of, e.g., a lack of hospital capacity. In Resilient Health Care theory, this difference is described as "work-as-imagined" and "work-as-done."[16] Healthcare professionals adjust to variations in situations and take advantage of next of kin competence for care tasks and observations but at the same time struggle with the accompanying emotional stress. This shows how healthcare professionals involve next of kin in their trade-offs to provide sound care quality.[37] Findings tied to work-as-imagined versus work-as-done and professional trade-offs also indicate that more attention should be given to the emotional stress that healthcare professionals experience to ensure that the stress does not drift into risk of failure and adverse events for patients with cancer.[38,39]

This study raises questions about next of kin involvement in cancer care and how to develop and cultivate teams around the patient that acknowledge the next of kin as co-creators of resilience. Resilience in this view requires learning from next of kin experiences; a set of skills to understand how next of kin as a practical resource contributes to the operational performance; find a balance between involvement and burden for next of kin; and, most importantly, acknowledge that next of kin, when involved, has the potential to enhance the quality and safety of patients with cancer.[6,18]

LIMITATIONS

First of all, when categorizing the data into the predefined categories of responding, monitoring, learning, and anticipation, we found examples where the categories appeared overlapping. This problem has been experienced by others,[40] and to ensure trustworthiness in the analysis, all three authors contributed in the analytical process and discussed potential challenges. Secondly, there may be variations across organizational levels (meso, micro) and between the hospitals in how next of kin contribute to cancer care, which cannot be detected by this study. However, because our data material was consistent between the studied entities here, we have chosen not to discuss this in our article. Still, we believe that there is a potential in exploring the differences between professional groups and between managers and healthcare professionals in how they consider the contribution from next of kin as co-creators of resilience.

CONCLUSIONS

Next of kin complement healthcare professionals in all four potentials for resilient performance (respond, monitor, anticipate, and learn). In this study, we suggest a further development of Hollnagel's four potentials for resilient performance.[22] This development can be considered a stakeholder potential that emerged through descriptions of how next of kin contribute to the provision of sound patient care under challenging conditions, possibly by expanding the RHC framework to include a potential for stakeholder involvement and collaboration. We demonstrate this in identifying nine areas in which next of kin co-create resilience. Moreover, further studies are needed to explore the stakeholder potential beyond next of kin (e.g., Fylan et al[33]), to generate new knowledge about how different stakeholders around the patient collaborate in and contribute to shaping resilience.

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Paper III

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ORIGINAL RESEARCH:
EMPIRICAL RESEARCH – MIXED METHODS

Measuring next of kin satisfaction with hospital cancer care: Using a mixed-method approach as basis for improving quality and safety

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Abstract

Aim/s: To explore next of kin satisfaction with cancer care, map next of kin suggestions for involvement and combine this information to create a basis for improving quality and safety in hospitals.

Design: Convergent parallel mixed-methods design applying the 20-item FAMCARE Scale survey instrument for quantitative measurement of satisfaction with care and with an open-ended question used for qualitative analysis.

Data sources: Responses from 238 next of kin (November 2016–November 2017).

Methods: Exploratory factor analysis, regression analysis and qualitative content analysis were combined.

Results: Both hospitals scored better in medical treatment (median, interquartile range: 1.5, 1.1–2.0), than in satisfaction with information and involvement of next of kin (1.9, 1.3–2.4), $p < .001$ (Wilcoxon signed ranks test). After adjusting for differences in demographical and clinical variables, the total FAMCARE scores were 13% higher (95% confidence interval: 1%–27%, Wald $p = .029$) at one of the hospitals. Qualitative findings support that the hospitals are not providing an equal offer to next of kin involvement in hospital cancer care that includes a proactive approach.

Conclusion: As a basis for quality and safety improvement, next of kin satisfaction and involvement in cancer care should be addressed in a two-sided perspective, balancing the next of kin's need for involvement in cancer treatment with the patient's perspective.

Impact: There is limited knowledge of next of kin satisfaction with hospital cancer care and how next of kin would like to be involved in this trajectory. Several aspects of satisfaction with cancer care can prompt change to improve service quality and safety (e.g. information, involvement, practical care), but this is an underused source of information. Next of kin are key in cancer care and our study demonstrates a

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potential large impact on future practical ways of improving cancer care service provision in an integrative perspective including next of kin.

KEYWORDS
cancer nursing, FAMCARE, hospitals, mixed method, next of kin, patient safety, quality, survey

1 | INTRODUCTION

Healthcare professionals often point to the next of kin as important collaborative partners in improving the quality and safety of hospital cancer care. At the same time, they are often excluded from systematic evaluations by the cancer care team (Bergerød, Braut, & Wiig, 2018b; Ekstedt, Stenberg, Olsson, & Ruland, 2014; Given, Given, & Sherwood, 2012). We know that the burden for next of kin, is challenging and may increase in the wake of changes in cancer care services where outpatient rather than inpatient clinics offer most treatment (Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013). Hence, next of kin face a complex set of challenges created by more aggressive treatment, earlier patient discharge and longer survival (Blindheim, Thorsnes, Brataas, & Dahl, 2013; van Ryn et al., 2011; Stenberg, Ruland, & Miaskowski, 2010; Thorsnes, Blindheim, & Brataas, 2014). The complexity of challenges and potentially both social and ethical implications for the next of kin are described by Tranberg, Andersson, Nilbert, and Rasmussen (2019) in terms of e.g. setting aside their own needs, having role as a project manager and losing sense of own identity (Tranberg et al., 2019).

2 | BACKGROUND

Next of kin are important in monitoring and managing the cancer patient's symptoms (Can et al., 2011; Kim & Yi, 2015). Several studies argue that healthcare systems should place greater emphasis on next of kin burden related to the trend of a more shared responsibility for the cancer patient (Litzelman, Kent, Mollica, & Rowland, 2016; Romito et al., 2013; Stenberg et al., 2010). Consequently, lack of structured next of kin involvement can cause anxiety and stress for the next of kin (McCarthy, 2011) and for healthcare professionals (Bergerød, Braut, & Wiig, 2018; Croskerry, Abbass, & Wu, 2010).

Theory and conceptual models on patient and public involvement, have been criticized for failing to embrace the complexity of involvement (Tritter, 2009). There is a tendency to assume that next of kin involvement is conducted for the next of kin themselves (McCarthy, 2011). There is, however developing evidence from studies arguing that next of kin involvement also affects quality and safety processes and outcomes for the patients (Aase, Laugaland, Dyrstad, & Storm, 2013; Ekstedt et al., 2014; Laidsaar-Powell et al., 2016).

Many healthcare organizations have recognized that user involvement can improve services quality and safety (Doyle, Lennox, & Bell, 2013; Lawton et al., 2017). Several studies argue that clinical effectiveness, patient safety and patient experiences have to be considered when working on improving care quality (Davis et al., 2013; Doyle et al., 2013; Wells, Campbell, Kumar, Clark, & Jean-Pierre, 2018). Other studies highlight the importance of using patient and stakeholder experiences as a basis for improvement (Davies & Cleary, 2005; Groene et al., 2014; O'Hara, Aase, & Waring, 2018). Here next of kin also play a key role.

Some knowledge exists about next of kin satisfaction with cancer care (Augustussen, Hounsgaard, Pedersen, Sjogren, & Timm, 2017; Can et al., 2011; Johnsen, Ross, Petersen, Lund, & Groenvold, 2012; Kim & Yi, 2015). Most of the research in this field has explored satisfaction with palliative care (Aspinal, Addington-Hall, Hughes, & Higginson, 2003; Dy, Shugarman, Lorenz, Mularski, & Lynn, 2008; Ringdal, Jordhoy, & Kaasa, 2002). There is however, limited knowledge about satisfaction with cancer care in a long-term setting (Rodriguez, Bayliss, Jaffe, Zickmund, & Sevick, 2010). In addition, there are, only a few studies on how data about satisfaction can be used to improve quality and safety in health care (Aspinal et al., 2003; Wells et al., 2018).

Although, mixed-method studies exits in the cancer area, there is only a limited amount of studies combining qualitative and quantitative data about next of kin satisfaction with care together with mapping their suggestions for involvement (Aspinal et al., 2003; Hannon et al., 2013; Partanen, Lemetti, & Haavisto, 2018). This indicates an unexplored potential for mixed-methods design looking into next of kin satisfaction with care and their interest in being involved.

3 | THE STUDY

3.1 | Aim/s

The aim of this study was to investigate next of kin satisfaction with cancer care and their suggestions for involvement in cancer care in two Norwegian university hospitals. Moreover, we aimed at combining this information as a basis for improving quality and safety in hospital cancer care. Our prior hypothesis was that next of kin would report high satisfaction, but we anticipated variations between hospitals and identification of new involvement methods that altogether could inform areas of improvement.

The following research questions (RQ) guided our study:

- RQ 1 What are the similarities and differences in next of kin satisfaction with cancer care in the two Norwegian hospitals?
- RQ 2 How would next of kin like to be involved in cancer care in the two Norwegian hospitals?

Based on the results of RQ 1 and RQ 2 we discuss how measuring next of kin satisfaction and identification of targeted next of kin involvement methods can inform cancer care improvement.

3.2 | Design and study setting

This study has a convergent parallel mixed-method study design (Creswell, 2014). Four cancer care inpatient units and three outpatient clinics in two university hospitals in Norway constitute the study setting. The hospitals were selected because they are comparable in size, structure and have the same external context belonging to the same health region (see also (Bergerød, Gilje, et al., 2018b).

This article is designed with a convergent design with a questionnaire variant. The mixed-method approach in this article explores quantitative measures assessed by surveying next of kin satisfaction in two hospitals, supported by qualitative text variables embedded in the survey questionnaire to identify possible ways of involving next of kin. We considered the qualitative component as an important way of identifying ways of improving satisfaction, involvement and quality and safety (Bergerød, Braut, et al., 2018; Bergerød, Gilje, et al., 2018b; Doyle et al., 2013). The quantitative component was the main driver in the study, but both the quantitative and qualitative results were important in the discussion section where they were integrated and supplement each other, as suggested as a way of mixing results in these types of designs (Creswell, 2014). The advantage of this approach was to strengthen the understanding of the quantitative results and the possible differences between the two hospitals, with qualitative interpretation and explanations (Creswell, 2015; O'Cathain, Murphy, & Nicholl, 2010; Östlund, Kidd, Wengström, & Rowa-Dewar, 2011).

3.3 | The questionnaire survey

In the first part of the survey questionnaire, the next of kin were asked to disclose information about themselves and the patient. We mapped the next of kin's variables: age, gender, relationship(s) to the patient, children living at home, highest degree of education and length of employment. For the patients we mapped the variables: age, gender, diagnosis and length of contact with the cancer department.

The survey instrument was the 20-item FAMCARE Scale. The FAMCARE scale was developed to measure family satisfaction with advanced cancer care (Kristjanson, 1993; Ringdal et al., 2002; Ringdal, Jordhoy, & Kaasa, 2003). Satisfaction of care is a frequently used outcome measure to evaluate how patients and/or family members evaluate the care they are given (Dy et al., 2008; Ringdal et al., 2002). Satisfaction with care in this study covers a broad range of items relevant for cancer care services (e.g. availability, service, information, care and involvement). We used the Norwegian survey version translated and validated by Ringdal and colleagues (Ringdal et al., 2002, 2003). In this version, item Q9 replaces the original term 'doctors' with 'healthcare professionals'. Twenty aspects of cancer care are considered by using a 5-point Likert format (a) very satisfied; (b) satisfied; (c) undecided; (d) dissatisfied; and (e) very dissatisfied. This was done in other studies (Can et al., 2011; Ringdal et al., 2002). We also provided an alternative, 'not relevant', as recommended in FAMCARE guidelines (Beaumont & Nekolaichuk, 2019). Additionally, we incorporated the open-ended questions: *Based on your experience, how should involvement of next of kin be done to improve quality and safety in cancer care? Do you have any specific suggestions?* The next of kin were given space in which to reflect and elaborate on their responses. All data were collected in parallel by responding to the survey.

3.4 | Sample/ Participants

A consecutive sampling strategy was used (Polit & Beck, 2014). We recruited next of kin to patients with a cancer diagnosis in different stages of the cancer care trajectory. Further inclusion criterion for patients and next of kin was to have been in contact with the hospital with a minimum of 3–6 months. The next of kin had to be over the age of 18, be able to give informed consent and be able to read and write Norwegian. During the recruitment, 250 patients and their next of kin were contacted at each hospital between November 2016 and November 2017. A total of 238 next of kin from both hospitals responded.

3.5 | Data collection

Appointed healthcare professionals at seven inpatient and outpatient wards at the two university hospitals invited patients to participate in the study. After obtaining patient consent, the healthcare professionals approached each patient's next of kin and asked if they were willing to complete a questionnaire. The healthcare professionals were given informal training on how to administer the questionnaire.

4 | ETHICAL CONSIDERATIONS

The questionnaires were completed anonymously and the only identifying information was the name of the hospital ward. The questionnaires were returned in a sealed envelope to the ward, or mailed in a prepaid envelope directly to the researcher (IJB). The Regional Committee for Medical and Health Research Ethics in Norway (2015/1488) approved the study. Participation in the study was based on voluntary recruitment and informed consent from the patient and next of kin. The data protection officers in both hospitals approved the project and thereby ensured permission from the hospitals.

5 | DATA ANALYSIS

5.1 | Quantitative data analysis

We used IBM SPSS v. 24 for statistical analysis unless otherwise noted. Participants with missing data on the variables involved in a particular model were excluded per analysis (available case analysis). $p \leq .05$ was considered statistically significant. Descriptive statistics of demographic and clinical variables and individual items' scores for the FAMCARE scale are presented as means and standard deviations (*SD*) and as counts and percentages. Item responses 'Not Relevant' were treated as missing and excluded from further analyses. Percentages of next of kin responding as satisfied or very satisfied are presented for the individual hospitals and compared using Poisson regression with robust standard errors, thus reporting relative risks/probabilities (RR). Both unadjusted RRs and RRs adjusted for clinical and demographic variables are presented along with 95% confidence intervals (CI) and *p*-values from Wald tests.

An exploratory factor analysis was performed in R v. 3.4.1 with package psych (Revelle, 2018). Due to the ordinal nature of individual items, we analysed polychoric correlations. The number of factors was decided by parallel analysis (Horn, 1965), where for each factor the empirical eigenvalues were compared with the means of eigenvalues obtained from resampled data. We used various extraction methods, which gave consistent results; the presented results are from maximum likelihood extraction and applying Oblimin oblique (non-orthogonal) rotation. Missing data were excluded pairwise, meaning that the pairwise correlations were estimated with all available cases for the specific correlation. Item 14 was excluded from factor analysis, in accordance with (Ringdal et al., 2003). As a further exploration of the data, we grouped items that loaded ≥0.6 on a factor; and finally these group means and the mean satisfaction score using the total FAMCARE scale and while excluding item 14 were compared between hospitals and between categories of respondents and patients using linear regression. Due to skewness in these outcome variables, descriptive statistics are presented as medians and interquartile ranges (IQR) and the variables were log-transformed prior to the regression analysis. The regression coefficients obtained in this way have been exponentiated so that the presented results have the interpretation of approximately the percent difference in median outcome score (Barrera-Gómez & Basagaña, 2015). Results from both univariable and multivariable regression analyses are presented.

5.2 | Qualitative data analysis

The qualitative content analysis followed a four-step interpretive characterization of the content influenced by Graneheim and colleagues (Graneheim & Lundman, 2004). Step 1: Discovering meaning units in plain text; Step 2: Condensing the meaning units with underlying interpretations; Step 3: Open coding followed by defining sub-categories leading into categories on the manifest and descriptive level; Step 4: Comparison across the cases to rebuild emerging themes on a latent and interpretive level. IJB developed the analysis with several iterations with SW and GSB. Table 1 gives an example of the steps in the interpretive process.

5.3 | Side-by-side mixed-methods analysis

There are several ways of merging data in mixed-method analysis (Creswell, 2014; Fetters, Curry, & Creswell, 2013). For this study we merged the data from the statistical analysis of the survey results and the qualitative content analysis to address the aim of the study and understand how next of kin satisfaction and ways of involving next of kin can improve service quality and safety in cancer care. The qualitative analysis and quantitative analysis have been done separately and brought together in a side-by-side comparison in the discussion section as suggested by Creswell (2014). In the discussion

TABLE 1 Example of the content analysis process

Meaning unit (Plain text)	Condensed meaning unit Descriptions close to text	Condensed meaning unit with interpretation	Code	Sub-category	Category	Theme
Everything will be individual, depending on the patient and the next of kin. For my/our part: Certainly more clearly on what I as a next of kin can contribute to the treatment and rehabilitation process. I am feeling 'a little on the side'. I understand that the focus should be on the patient	Be clearer on what I as a next of kin can contribute to the treatment and rehabilitation process. I am feeling 'a little on the side'. I understand that the focus should be on the patient	Next of kin feel a little on the side. They have full understanding that the focus should be on the patient, but they need more clear descriptions about how they can contribute to the treatment and rehabilitation process	Next of kin have a role 'on the side'	Next of kin get too little education on how to help and ease the treatment even though a lot happens at home	Acting in the patients' best interest	'Neither in nor out of treatment processes'

we compare the results and note where there is convergence or divergence between them and how the qualitative findings confirmed, disconfirmed or added new dimensions to the results. We developed a model of the Involvement Pendulum to help understand the integration of results and the implications for cancer care (please see Figure 1).

5.4 | Validity and reliability/Rigour

During development of the scale, Kristjanson (1993) found the instrument to be valid and reliable for measuring next of kin satisfaction with advanced cancer care in Canada, with criterion validity in relation to the McCusker scale of about 0.8, a Cronbach's alpha of 0.93 and a 24-hr test–retest reliability of 0.92. The psychometric properties of the FAMCARE survey instrument were assessed by Ringdal et al. (2003) for use in advanced cancer care in the Norwegian context. They found that 19 out of 20 items would form a strong one-dimensional scale, with a weighted Loevinger's coefficient of homogeneity (H_{wgt}) of 0.59 and Cronbach's alpha of 0.93. The full scale was however found to be weak, with a H_{wgt} of 0.27. We have supplemented the questionnaire with open-ended questions to address any methodological issues with measuring satisfaction with care for cancer patients, as recommended in Willis, Evandrou, Pathak, and Khambhaita (2016).

The data were entered manually into a file IBM SPSS Statistics by IJB, and a random 10% sample was checked and found satisfactory by BG.

Trustworthiness in the qualitative analysis was ensured by member checks and discussion of preliminary results of the analysis in a one-day seminar with healthcare professionals and next of kin representatives from the two involved hospitals, in November 2018. In addition, authors discussed the findings and analysis in several meetings to ensure the quality of the content analysis (Patton, 1990).

6 | RESULT

6.1 | Quantitative results

6.1.1 | Sample characteristics of participants

The total study sample comprised 238 next of kin, amounting to a response rate among those recruited of 48%; 60% at hospital 1 and 36% at hospital 2. Table 2 summarizes the characteristics of the respondents with sociodemographic and clinical variables in the total sample and in the two case hospitals. In the total sample, the next of kin (N = 238) comprised 59% women and 41% men. The mean age was 60.2 years (SD 12.1). As many as 22.6% reported to be 70 years or older and 47.7% stated that they did not work. Most respondents were either the spouses or partners (74.8%) or adult children of the patient (14.7%). Almost half of the respondents (42.6%) had a college/university grade.

The distribution of the patients` gender was approximately even. The percentage of patients whose contact to the cancer department had been less than a year was 42.3%; 15.8% reported

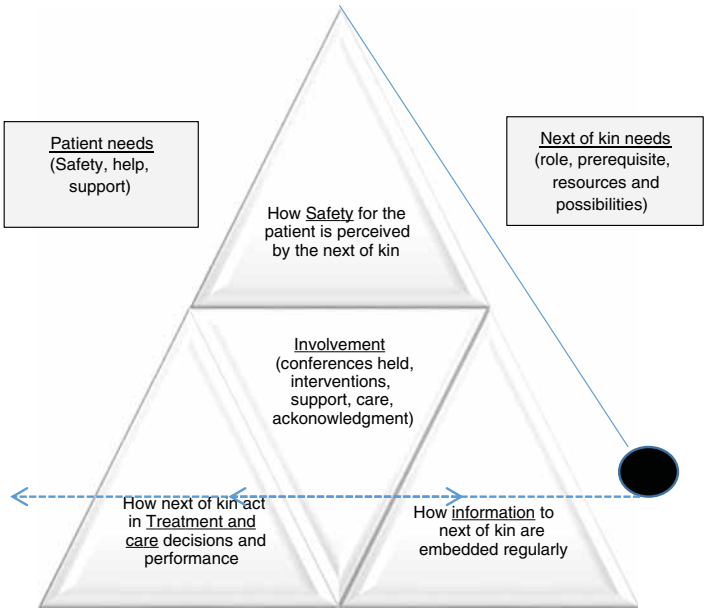

FIGURE 1 The involvement pendulum [Colour figure can be viewed at wileyonlinelibrary.com]

TABLE 2 Characteristics of the respondents and the patients

Variables	Total (*N* = 238)	Hospital 1 (*N* = 149)	Hospital 2 (*N* = 89)
Next of kin			
Age, years	(*N* = 235)	(*N* = 147)	(*N* = 88)
Mean (*SD*)	60.2 (12.1)	59.6 (12.0)	61.2 (12.0)
<40	8 (3.4%)	5 (3.4%)	3 (3.4%)
40–59	98 (41.7%)	63 (42.9%)	35 (39.8%)
60–69	76 (32.3%)	49 (33.3%)	27 (30.7%)
≥70	53 (22.6%)	30 (20.4%)	23 (26.1%)
Gender, women	141 (59.2%)	85 (57.0%)	56 (62.9%)
Relationship with patient	(*N* = 228)	(*N* = 144)	(*N* = 84)
Spouse/partner	178 (74.8%)	114 (76.5%)	64 (71.9%)
Child	35 (14.7%)	22 (14.8%)	13 (14.6%)
Parent	9 (3.8%)	4 (2.7%)	5 (5.6%)
Other	6 (2.5%)	4 (2.7%)	2 (2.2%)
Education	(*N* = 235)	(*N* = 147)	(*N* = 88)
Primary School	33 (14.0%)	19 (12.9%)	14 (15.9%)
High School	102 (43.4%)	68 (46.3%)	34 (38.6%)
College/university	100 (42.6%)	60 (40.8%)	40 (45.5%)
Employment	(*N* = 235)	(*N* = 147)	(*N* = 88)
Full-time	93 (39.6%)	56 (38.1%)	37 (42.0%)
Part-time	30 (12.8%)	22 (15.0%)	8 (9.1%)
None	112 (47.7%)	69 (46.9%)	43 (48.9%)
Patient			
Age, years			
Mean (*SD*)	64.3 (12.5)	64.4 (11.6)	64.2 (14.1)
<50	25 (10.5%)	16 (10.7%)	9 (10.1%)
50–69	122 (51.3%)	75 (50.3%)	47 (52.8%)
≥70	91 (38.2%)	58 (38.9%)	33 (37.1%)
Gender, women	112 (47.1%)	73 (49.0%)	39 (43.8%)
Type of ward, inpatient	103 (43.3%)	48 (32.2%)	55 (61.8%)
Diagnosis			
Gastrointestinal cancer	40 (16.8%)	17 (11.4%)	23 (25.8%)
Pancreatic cancer	14 (5.9%)	8 (5.4%)	6 (6.7%)
Breast cancer	33 (13.9%)	29 (19.5%)	4 (4.5%)
Prostate cancer	11 (4.6%)	6 (4.0%)	5 (5.6%)
Haematological cancer	61 (25.6%)	52 (34.9%)	9 (10.1%)
Melanoma	11 (4.6%)	9 (6.0%)	2 (2.2%)
Other cancer	29 (12.2%)	12 (8.1%)	17 (19.1%)
Not specified	39 (16.4%)	16 (10.7%)	23 (25.8%)
Duration of contact, years	(*N* = 234)	(*N* = 147)	(*N* = 87)
<1.0	99 (42.3%)	56 (38.1%)	43 (49.4%)
1.0–1.9	37 (15.8%)	22 (15.0%)	15 (17.2%)
2.0–4.9	61 (26.1%)	46 (31.3%)	15 (17.2%)
≥5.0	37 (15.8%)	23 (15.6%)	14 (16.1%)

Note: SD Standard deviation. Data are presented as count (percentage) unless otherwise specified. The number of non-missing cases is indicated for variables with missing data.

that their contact with the cancer department had been five years or more. The most frequent cancer diagnoses among the patients were haematological (33.3%), gastrointestinal (21.9%) and breast cancer (18.0%). However, a large group in the sample (13.4%) did not report a specific diagnosis beyond cancer. In hospital 2, 39.3% of respondents (N = 88) did not state a specific diagnosis.

6.2 | Satisfaction with care based on individual items

Table 3 (Figure S1) gives an overview of the scores on individual items in the FAMCARE scale based on the total sample of 238 participants and shows that in all items most respondents reported to be satisfied or very satisfied. The highest satisfaction with care (satisfied/very satisfied >90%) was found in Q6 (Availability of a hospital bed) and Q12 (Availability of nurses to the family). The items with the lowest satisfaction with care (dissatisfied/very dissatisfied >15%) were found in Q7 (Family conferences held to discuss the patient`s illness) and Q14 (Time required to make a diagnosis).

Overall, there were 9.6% missing responses on the FAMCARE scale questions, mostly due to respondents answering 'Not Relevant' (7.4%). The number of missing responses varied substantially among the items, with ≤6% missing on 12 items and ≥25% missing on Q15 (The way the family is included in treatments and care decisions) and Q16 (Information given about how to manage the patient's pain).

For all individual items, there was an observed 10–40% higher percentage of satisfied or very satisfied next of kin in hospital 1 than in hospital 2 (observed RRs between 1.1 & 1.4) (Table S1). After adjustment for next of kin-related (age, gender, education and relationship with the patient) and patient variables (age, gender, diagnosis, duration of contact with the ward and inpatient vs. outpatient ward), there were statistically significant differences between the two hospitals in items Q3 (Answers from healthcare professionals), Q12 (Availability of nurses to the family), Q13 (Coordination of care), Q15 (The way the family is included in treatments and care decisions), Q18 (How thoroughly the doctor assesses the patient's symptoms) and Q20 (Availability of the doctor to the patient). The largest difference was found for Q15 with a 30% increased probability of being satisfied or very satisfied at hospital 1 (RR 1.3, 95% CI 1.1–1.7, p = .013).

6.3 | Factor analysis

In an exploratory factor analysis, we obtained two factors (Table 4). Inspection of factor loadings revealed a pattern where items loading high on factor F1 seemed to regard information and involvement of the next of kin; items loading high on factor F2 were related to the medical treatment of the patient.

6.4 | Satisfaction with care based on summary scores

The scores were higher on involvement related items (median 1.9, IQR 1.3–2.4) than on treatment related items (1.5, 1.1–2.0), $p < .001$ (Wilcoxon signed ranks test); indicating more satisfaction with treatment (Table 5). Hospital 1 scored better on all summary scores; the observed median scores were 15%–17% higher in hospital 2, indicating greater dissatisfaction. The differences were reduced after adjustment for demographic and clinical variables; however, they remained statistically significant for all summary scores apart from the involvement-related items (Table 5).

Regarding the demographic and clinical variables, some statistically significant differences in satisfaction were seen for the FAMCARE total summary score (with and without Q14) and for involvement-related but not for treatment-related items (Table S2). The older respondents (≥60 years) were more satisfied, with median scores 16%–28% lower than those of the reference group (40–59 years). In addition, the next of kin were more satisfied when patients were in an outpatient ward (median scores 13%–19% lower). A tendency for greater satisfaction among next of kin with less education disappeared when adjusting for the other variables. The full models, including hospital as explanatory variable, explained 20%–21% of the variance in (log transformed) total summary scores and care-related items but only 12% of the variance in treatment-related items (Table S2).

6.5 | Qualitative results

One hundred next of kin (52 from hospital 1 and 48 from hospital 2) answered the open-ended questions in the questionnaire. The analysis of the qualitative data resulted in three common themes for both hospitals, describing the visibility of the next of kin role in the cancer care trajectory. Table 6 gives an overview of sub-categories, categories and themes. Further, based on findings in the analysis, the three themes are presented with categories and examples of quotes to illustrate satisfaction with care, involvement and suggestions for ways of improving this in cancer care.

6.6 | Being on parallel information tracks

This theme described what the next of kin considered important quality and safety measures for the patients in the cancer care trajectory.

6.6.1 | Guardians in the cancer care trajectory

Results showed that many respondents considered themselves the guardians of the patient. To become and remain an important resource for the patient and the healthcare system, these respondents noted that information adapted to their role, resources and capability was crucial. They argued that their information needs as the

TABLE 3 Details of Responses to the individual items of the FAMCARE scale

Item	Explanation	*n*	NR (%)	Miss (%)	Mean (*SD*)	% Satisfied		% Dissatisfied	
						1 + 2	1	4 + 5	5
Q1	The patient's pain relief	196	16.8	0.8	1.62 (0.77)	87.8	53.1	2.0	0.5
Q2	Information given about the patient's prognosis	235	0.8	0.4	1.89 (0.95)	77.4	41.5	6.8	1.3
Q3	Answers from healthcare professionals	227	3.8	0.8	1.76 (0.85)	84.1	44.5	2.6	1.8
Q4	Information given about side effects	230	2.1	1.3	1.95 (0.95)	77.0	36.5	6.5	2.2
Q5	Referrals to specialists	189	16.8	3.8	1.67 (0.86)	87.8	51.1	3.7	2.1
Q6	Availability of a hospital bed	207	10.9	2.1	1.40 (0.69)	96.6	66.5	1.9	1.5
Q7	Family conferences held to discuss the patient's illness	189	17.6	2.9	2.29 (1.21)	65.1	30.2	15.3	8.5
Q8	Speed with which symptoms are treated	230	1.7	1.7	1.91 (1.11)	76.4	47.6	10.5	4.4
Q9	Doctor's attention to patient's description of symptoms	235	1.3	-	1.51 (0.78)	89.4	62.6	2.1	0.9
Q10	The way tests and treatments are performed	234	0.4	1.3	1.50 (0.62)	94.0	56.4	0.4	-
Q11	Availability of doctors to the family	212	9.2	1.7	2.08 (1.03)	70.3	34.4	9.4	2.8
Q12	Availability of nurses to the family	213	10.1	0.4	1.61 (0.84)	89.2	55.9	4.2	1.4
Q13	Coordination of care	227	3.8	0.8	1.62 (0.85)	88.1	54.9	2.7	2.2
Q14	Time required to make a diagnoses	223	2.9	3.4	2.23 (1.38)	70.3	40.5	20.7	12.6
Q15	The way the family is included in treatments and care decisions	170	23.1	5.5	2.00 (0.92)	77.1	31.2	5.9	2.4
Q16	Information given about how to manage the patient's pain	178	21.4	3.8	2.10 (1.13)	70.2	36.5	10.1	6.2
Q17	Information given about the patient's test	226	2.5	2.5	1.88 (0.96)	81.0	40.3	5.3	3.5
Q18	How thoroughly the doctor assesses the patient's symptoms	226	1.3	3.8	1.77 (0.84)	82.3	44.7	3.1	0.9
Q19	The way tests and symptoms are followed up by the doctor	230	0.4	2.9	1.62 (0.76)	88.2	51.5	1.3	0.9
Q20	Availability of the doctor to the patient	228	0.8	3.4	1.78 (0.84)	83.7	42.3	3.1	1.3

Note: The options for each item were: Very satisfied (score 1); Satisfied (2); Undecided (3); Dissatisfied (4); and Very dissatisfied (score 5).

Abbreviations: *n*, Number of available and analysed responses; NR, Not Relevant; Miss, Missing response; *SD*, Standard deviation.

TABLE 4 Results from factor analysis of the FAMCARE scale

Item	Explanation	*n*	Factor loadings F1	F2
Q1	The patient's pain relief	196	−0.01	**0.77**
Q2	Information given about the patient's prognosis	235	**0.73**	0.09
Q3	Answers from healthcare professionals	227	**0.63**	0.25
Q4	Information given about side effects	230	0.34	0.39
Q5	Referrals to specialists	189	−0.03	**0.78**
Q6	Availability of a hospital bed	207	−0.12	**0.75**
Q7	Family conferences held to discuss the patient's illness	189	**0.87**	−0.13
Q8	Speed with which symptoms are treated	230	0.04	**0.68**
Q9	Doctor's attention to patient's description of symptoms	235	0.17	**0.69**
Q10	The way tests and treatments are performed	234	0.26	0.57
Q11	Availability of doctors to the family	212	**0.95**	−0.04
Q12	Availability of nurses to the family	213	**0.82**	−0.01
Q13	Coordination of care	227	0.40	0.49
Q14	Time required to make a diagnoses	223	-	-
Q15	The way the family is included in treatments and care decisions	170	**0.82**	0.03
Q16	Information given about how to manage the patient's pain	178	**0.73**	0.13
Q17	Information given about the patient's test	226	**0.83**	0.07
Q18	How thoroughly the doctor assesses the patient's symptoms	226	0.05	**0.85**
Q19	The way tests and symptoms are followed up by the doctor	230	−0.07	**0.96**
Q20	Availability of the doctor to the patient	228	0.32	0.59

Factor analysis applying polychoric correlations, maximum likelihood extraction and parallel analysis to decide number of factors. Factor loadings by Oblimin rotation. Missing data were excluded pairwise. Item 14 was not included in the analysis. Factor loadings in boldface (≥0.6) indicate the items included in subtotals.

TABLE 5 Overview and comparison of hospitals on summary scores from the FAMCARE scale

FAMCARE items	n_1/n_2	Total Median (IQR)	Hospital 1 Median (IQR)	Hospital 2 Median (IQR)	Unadjusted % diff (95% CI)	*p*	Adjusted* n_1/n_2	Adjusted* % diff (95% CI)	*p*
Total	141/87	1.7 (1.3, 2.2)	1.6 (1.2, 2.1)	1.9 (1.4, 2.4)	17 (7, 29)	.001	131/79	13 (1, 27)	.029
Total without item Q14	143/87	1.7 (1.2, 2.2)	1.6 (1.2, 2.1)	1.9 (1.3, 2.4)	17 (7, 29)	.001	133/79	13 (1, 26)	.034
Treatment-related items	142/86	1.5 (1.1, 2.0)	1.4 (1.0, 2.0)	1.7 (1.2, 2.2)	15 (5, 27)	.003	132/78	14 (1, 29)	.032
Involvement-related items	132/83	1.9 (1.3, 2.4)	1.7 (1.3, 2.2)	2.0 (1.4, 2.6)	17 (5, 30)	.005	123/76	11 (−3, 27)	.13

Note: n1 Number of analysed cases from Hospital 1, n2 Number of analysed cases from Hospital 2, IQR Inter quartile range, diff Difference, CI Confidence interval, p P-value from Wald test. All summary scores calculated with requirement > 60% valid responses for the included items. Treatment-related items: Q1, Q5, Q6, Q8, Q9, Q18 and Q19. Involvement-related items: Q2, Q3, Q7, Q11, Q12, Q15, Q16 and Q17. Mean scores have been log-transformed prior to analysis, and the presented effects are exponentiated beta coefficients from linear regression which are approximately the percent difference in medians25.

*Adjusted for next of kin related variables: age, gender, education, relationship with the patient; and patient variables: age, gender, diagnosis, duration of contact with the ward and type of ward (outpatient vs. inpatient). Participants missing data for any of the variables involved in a particular model were excluded.

next of kin differ from the information needs of the patient. Results also showed that the handling of information needs by healthcare professionals was essential for next of kin's satisfaction with patient safety in the hospitals:

> Even if the patient does not want to know that the end is coming, you should ask the next of kin if they want to know. I feel that the doctor is less available to answer honest and specific questions.

TABLE 6 Overview of sub-categories, categories and themes

Themes	Being on parallel information tracks	Neither in nor out of treatment processes	The act of balancing involvement needs
Categories	Guardians in the cancer care trajectory	Acting in the patients' best interest	The proactive approach
Sub-categories	Next of kin need different information than the patient Next of kin suggest they should have their own designated consultation In case of critical illness, it should not be only up to the patient to decide if the next of kin should get information. Next of kin need regular information on pathology, treatment options, side effects and patient case history	Involvement in treatment and care processes can be crucial for the recovery process. Next of kin suggest more systematic training in how to contribute in the treatment process If next of kin are properly involved, adverse events might possibly be prevented	Next of kin see themselves as an important source of knowledge and as a collaborative partner with healthcare professionals A cancer diagnosis involves the whole family When next of kin are involved they are more satisfied with patient care Families with children and older people need closer attention and involvement

In other words, next of kin perceived themselves on a parallel track with the patient but with different information needs. They suggested having their own private conversation with healthcare professionals. Some respondents even claimed that it should not just be up to a critically ill patient to decide who should get information. They argued that next of kin depend on information to live up to their responsibilities as part of the treatment process. They added that they needed to be updated regularly by healthcare professionals on the patient's pathology, treatment options, side effects and especially if there were any changes in the patient's case history, including cognitive status:

> Important to get information on treatment options and development of the illness. It can be difficult to understand what happens and why if something is being changed.

6.7 | Neither in nor out of treatment processes

This theme focused on the next of kin roles, contribution and the possible impact on patient outcome.

6.7.1 | Acting in the patient's best interest

The respondents described how they stood side-by-side with the patient throughout the entire treatment process. They tried to understand and act in the patients` best interest, often with incomplete information and their own lay interpretations of the patient's condition. The results also showed that if the next of kin were in line with the patient, adverse events might be prevented. For example, if the healthcare professionals collected next of kin opinions of and experiences with the patient, they could gain important insights into the decision-making processes by better understanding the patient`s status:

> When the patient has reached a certain age as in our case, it is important that next of kin get complete information. We (next of kin) can also have important information to give the doctor on how the patient is doing at home. If the information is given only to the patient, things may go wrong. The patient might not able to comprehend all of the information and ask the right questions.

The results showed that the next of kin considered themselves an extension of the healthcare professional team, but the descriptions also showed their dissatisfaction with being in a kind of limbo. On the one hand, they were not healthcare professionals and on the other, they were not the patient. As such, they were neither inside nor outside of the treatment process. The respondents repeatedly insisted that next of kin involvement in the patients` treatment and care could be crucial for the patient's recovery:

> As a next of kin, you really get little information that is aimed at you on how to help and ease the treatment even if a lot happens at home.

6.8 | The act of balancing involvement needs

This theme represents a bridge between the two other themes. The two other themes focused more on patient outcome, next of kin roles and expectations for the patient's sake, but this theme describes the importance of involving the next of kin for their own sake as key to their satisfaction with cancer care.

6.8.1 | The proactive approach

Next of kin considered themselves as an important source of knowledge and a partner with the team of healthcare professionals. Next of kin described that if they were more systematically involved as collaborative partners it could have positive consequences not only for patient outcome, but also for themselves. A serious cancer diagnosis involves the patient's whole family, but affects each member

in a different way, they argued. The respondents claimed that they would feel less anxious if they were more involved in decision-making, kept updated on the patient's status and trained in meeting the patient's needs. This theme showed how next of kin's involvement was in their own and the patient's best interest. The result showed that when next of kin were involved, they tended to be more satisfied with the care being given. However, the results indicated a need to offer tailored interventions to families with minor children and adult next of kin to older patients. These interventions should be balanced and customized to the individual patient and next of kin needs:

> Next of kin should have the opportunity to follow the patient to treatment, consult with the doctor or other healthcare professionals. We need our own consultations as soon as possible. I believe there are more questions from the next of kin than from the patient. Next of kin will continue living after the patient has passed away.

7 | DISCUSSION

To our knowledge, this is the first mixed-method study measuring next of kin satisfaction with cancer care in two hospitals. The quantitative results confirmed our prior hypothesis, that next of kin would report high satisfaction with care in both hospitals. This is consistent with other studies reporting high satisfaction from next of kin (Johnsen et al., 2012; Ringdal et al., 2002). We have demonstrated how next of kin satisfaction with hospital cancer care can be measured by the FAMCARE survey instrument that is also supplemented with open-ended questions about relevant next of kin involvement methods. This was done to address any methodological issues by measuring satisfaction (Willis et al., 2016). How to integrate the next of kin perspectives, satisfaction and identifying ways of being involved in health care, quality and safety activities is not well-understood (Vincent & Davis, 2012). This study demonstrates a possible way forward for practitioners and gives ideas for future research in larger multicentre studies. We argue that the issue of satisfaction is not always necessarily a key in itself; it needs to be conceptualized in a service setting or activity. Therefore, data on satisfaction or other experiences could be applied in feedback processes, as a basis for indicating where service providers should focus on keeping up good results and identify areas with obvious room for improvement (Fisher & Mazor, 2017; Hollnagel, 2017).

Our study is consistent with another study showing high levels of next of kin dissatisfaction in Q14 (Time to make a diagnosis) and Q7 (Family conferences held to discuss the patient`s illness; Johnsen et al., 2012). Our qualitative results confirmed the challenges with family conferences and lack of involvement. However, our study also contributed to identify new solutions since our respondents suggested to establish specific meetings with next of kin and healthcare professionals, without the patient present.

The highest levels of satisfaction in our study were found in Q6 (Availability of a hospital bed) and Q12 (Availability of nurses to the family). In a study from 2010 (Rodriguez et al., 2010) where the FAMCARE instrument was tested in a long-term cancer setting, these two items were found to correlate weakly with the instrument total. In our study, Q6 was strongly correlated to the Treatment factor and Q12 was strongly correlated to the Involvement factor.

We found that satisfaction with care increased with age and next of kin were more satisfied with outpatient than with inpatient wards. However, here we experienced that there was a divergence from the qualitative data. In the qualitative data we found, in line with other studies, that families with an older patient need closer attention and tailored interventions (Nyborg, Danbolt, & Kirkevold, 2017; Storm, Siemsen, Laugaland, Dyrstad, & Aase, 2014). This indicates that hospital cancer care could focus more on older groups of patients and more tailored interventions, to keep satisfaction at a high level.

Among the individual items, we found significant differences between the two hospitals that might be of clinical relevance, i.e. in Q3 (Answers from healthcare professional), Q12 (Availability of nurses to the family), Q13 (Coordination of care), Q15 (The way the family is included in treatment and care decisions), Q18 (How thoroughly the doctor assesses the patient's symptoms) and Q20 (Availability of doctor to the patient). None of these items were among the survey items with the least satisfaction with care, but do nevertheless indicate a potential for improvement.

We found two factors in the exploratory analysis (treatment vs. involvement) but other FAMCARE studies have found others (Kristjanson, 1993; Ringdal et al., 2003). Some of these factors have similarities to ours, especially in terms of information. We have labelled one factor 'involvement', because it relates to information needs and being involved and informed. The previous studies, were performed before patient and next of kin participation had become key issues on the health policy agenda (Norwegian Ministry of Health & Care Services, 2015). If they had performed the studies today, the interpretation might have been different. Since 2003 there has been a movement towards more involvement of next of kin in cancer treatment and care (Norwegian Ministry of Health & Care Services, 2013–2017; Romito et al., 2013) and in health services generally (Norwegian Ministry of Health & Care Services, 2011; Tritter, 2009).

Further, our analyses showed that next of kin in both hospitals scored satisfaction better in treatment of the patients, compared with information and involvement of next of kin. This indicates that hospital cancer care should pay more attention to involvement related items (F1) to improve care quality, in addition to sustaining the high scores obtained in treatment related items (F2). This need for involvement and new ways of involvement were also confirmed by our qualitative results. The higher quantitative score on satisfaction with treatment was supported by our qualitative results, indicating that next of kin could probably score even higher on the treatment items if they were stronger integrated into the treatment process and in the treatment team. Our results found that they experienced being on parallel tracks.

7.1 | Integration of results – Next of kin involvement from a two-sided perspective

In the previous decades the involvement of patients and the public in performing health care was encouraged due to a diversity of reasons, e.g. treatment decisions, service development, evaluation of services, education and training (Tritter, 2009). Based on our findings, we argue that the same reasons could be considered in questions of involving the family and next of kin in a patient's cancer care. One may claim that the role of the next of kin is integrated with the role of the patient. Based on our findings, we argue that the perspective of the next of kin should be made more explicitly visible to acknowledge and understand the complexity in the next of kin's role and reasons for involvement in cancer care (O'Hara et al., 2018).

In this study the qualitative results show that next of kin felt 'Neither in nor out of treatment processes' and have a sense of 'Being on parallel information tracks'. The description of the qualitative results categorized under these two themes, confirms and gives more insight into the result of the quantitative analysis showing that next of kin are more satisfied with treatment-related items than involvement-related items. The qualitative results show that next of kin were dissatisfied and struggling to take care of their own well-being (role, prerequisite, resources and opportunities) and the patient's needs (safety, help and support). In other words, the next of kin role and their satisfaction with cancer care services have dual characteristics.

The next of kin have their own needs and interests. Thus, the next of kin should be acknowledged having their own role, not merely as a part of the patients' role. This perspective opens up for an understanding of possible conflicts of interest between the role of the patient and the role of the next of kin. Based on our findings we therefore argue that next of kin satisfaction and involvement should be addressed from a two-sided perspective, balancing the needs of the next of kin with those of the patient. Such a balanced approach may improve both next of kin satisfaction with cancer care and improve service quality and safety.

To visualize our perspective, we developed a conceptual model (Figure 1). The involvement pendulum illustrates that the perception of satisfaction with cancer care, quality and safety and appropriate methods of involvement, will change with the swinging of the pendulum.

The corners of the triangle in Figure 1 depict three areas which are bridging the quantitative results of the factors 'Treatment' and 'Involvement', with qualitative results about what next of kin describe as important in terms of their own role and contribution and improving quality and safety in hospital cancer care. The three corners are: (a) Safety – which relates to how next of kin perceive quality and safety in hospital cancer care given to the patient; (b) Treatment/care – which relates to how next of kin act in treatment and care decisions and performance; (c) Information – which is a prerequisite factor for involvement and how next of kin act in treatment and care decisions and performance.

We argue that the center of the triangle, involvement, should receive more attention by cancer care services to ensure a balanced involvement of next of kin adjusted to the individual patient cases. Our model can help hospital cancer care services in tailoring next of kin involvement initiatives for the next of kin themselves (e.g. own consultation) and for the patient (e.g. interventions with special training that supports both next of kin and patient needs).This might have the potential of closing the gap on unsuccessful caregiver interventions in cancer care services (Ugalde et al., 2019).

7.2 | Clinical implications and future research

Anchored in our findings, we suggest a structural change in evaluation of cancer care services including measurement of next of kin satisfaction and experiences in addition to the patient voice in user surveys. The FAMCARE survey instrument could be adapted into patient user surveys in cancer care departments. To be meaningful for cancer care services, survey results should be applied at the ward and department levels. Previous research shows that this will effect change in practice (Bate, Mendel, & Robert, 2008; Kringos et al., 2015). Based on findings of differences with satisfaction with the care given in cancer departments in the same regional health trust in Norway, our study identified differences in how hospitals handle next of kin involvement. We recommend that hospital cancer care departments should strive to give next of kin with an equal offer (e.g. regular meetings, individual follow-up, similar information sources) and collaborate across disciplines and organizations in their provision of systematic next of kin involvement. This can contribute in a direction of meeting overall governmental expectations of more involvement (Norwegian Ministry of Health & Care Services, 2013–2017); and embrace the proactive approach suggested by next of kin in this study. Future research should further explore how next of kin experiences can influence and improve cancer care quality and safety (O'Hara, Canfield, & Aase, 2019). A possible way forward could be to develop a targeted questionnaire with this specific purpose, or to use the FAMCARE scale with a mixed-method approach as we have demonstrated in this study in larger studies that compare several hospitals and in cross country studies.

7.3 | Limitations

This study explored cancer departments in two Norwegian hospitals and ha several limitations. First, there might be variations across cancer care departments that this study failed to detect. Second, we have included next of kin of patients who are at different points in the cancer care trajectory, although the FAMCARE scale was developed for patients in the advanced stages of cancer. Third, the low response rates, especially in hospital 2 and the high percentage of missing responses in some of the FAMCARE items, may have biased our findings. The largest proportions of missing observations in this study was found in Q15 (The way the family is included in treatment and

care decisions) and Q16 (Information given about how to manage the patient's pain). In retrospect, this was not a surprise since both items are dependent on external factors to be relevant to the respondents (e.g. if the patient has experienced pain, or if the family has been invited to take part in decision processes). This could be confusing for the respondent and indicative of a possible methodological problem with the FAMCARE instrument. Descriptions of this problem are to our knowledge lacking in the literature on the instrument. For future studies using FAMCARE, we recommend an open-ended section that elaborates on the individual items for better understanding the respondent's reasons for responding that a question is 'not relevant'. Finally, our mixing of the quantitative and qualitative results in the discussion section was performed according to Creswell (2014). It is a known limitation that this kind on mixing can have limitations with topics where there is discrepancy between the qualitative and quantitative results. This could be a limitation in our study as well, however we have tried to reduce this to a minimum by having several rounds of discussions in the author team and all authors have been involved in the analysis and interpretation of results from the design to the final reporting of the study.

8 | CONCLUSION

In this study we demonstrated how measuring next of kin satisfaction on the 20-item FAMCARE scale can work as a basis for improving quality and safety in hospital cancer care. We found that next of kin had a high degree of satisfaction with cancer care services in both hospitals, but there were some areas that had room for improvement. The mix of quantitative and qualitative measurements indicated that next of kin were involved in different ways in the cancer care departments. The differences revealed a lack of systematic involvement of next of kin on their own terms and for the patient's sake. Next of kin expressed higher satisfaction on treatment items than on involvement items, implying a need for more attention to develop new and sound ways to involve the next of kin to improve both satisfaction and service quality and safety.

In addition, next of kin in this study insisted that a private conversation with their patient's healthcare team would increase their satisfaction with cancer care. Such a conversation could acknowledge the next of kin role as a natural part of the interdisciplinary medical team around the patient. In a Norwegian context this would require a legal change in the rights of the next of kin.

CONFLICTS OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

IJB; ID; GSB; SW: Made substantial contributions to the conception and design, acquisition of data and analysis and interpretation of data; IJB; ID; GSB; BG; SW: Involved in drafting the manuscript or revising it critically for important intellectual content; IJB; ID; GSB; BG; SW: Gave final approval of the version to be published. Each author should participated sufficiently in the work to take public responsibility for appropriate portions of the content; IJB; ID; GSB; BG; SW: 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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Paper IV

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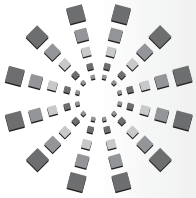

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Developing a Next-of-Kin Involvement Guide in Cancer Care—Results From a Consensus Process

KEY WORDS
Cancer nursing
Consensus methods
Guide
Hospitals
Involvement
Next-of-kin
Nominal group technique

Background: In hospital cancer care, there is no set standard for next-of-kin involvement in improving the quality of care and patient safety. There is therefore a growing need for tools and methods that can guide this complex area. **Objective:** The aim of this study was to present the results from a consensus-based participatory process of designing a guide for next-of-kin involvement in hospital cancer care. **Method:** A consensus process based on a modified Nominal group technique was applied with 20 stakeholder participants from 2 Norwegian university hospitals. **Result:** The participants agreed on the 5 most important priorities for hospital cancer care services when involving next-of-kin. The results showed that next-of-kin stakeholders, when proactively involved, are important resources for the patient and healthcare professionals in terms of contribution to quality and safety in hospitals. Suggested means of involving next-of-kin were closer interaction with external support bodies, integration in clinical pathways, adjusted information, and training healthcare professionals. **Conclusion:** In this study, we identified topics and elements to include in a next-of-kin involvement guide to support quality and safety in hospital cancer care. The study raises awareness of the complex area of next-of-kin involvement and contributes with theory development and knowledge translation in an involvement guide tailored for use by healthcare professionals and

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The authors have no conflicts of interest to disclose.

The study was approved by the Regional Committee for Medicine and Health Research Ethics in Norway (2015/1488). Consent from study participants was confirmed and accepted by email. All participation in the study is based on voluntary recruitment. The project has also been approved by the data protection officers at the 2 case hospitals.

The dataset used and analyzed during this study is available from the corresponding author on reasonable request.

Authors' contributions: IJB contributed to the study design, data collection, moderating in the consensus process, and analysis and interpretation of data and wrote the manuscript. SW contributed to the study design, data collection, analysis and interpretation of data, moderating the consensus process, and preparation of the manuscript. GSB contributed to the analysis and interpretation of data and moderating the consensus approach and commented on the drafts of the manuscript. BG contributed with moderating the consensus approach with analysis and with interpretation of data and has commented on manuscript drafts. BF coordinated the recruitment process in 1 hospital, was a nonparticipant observer of the consensus process, and has commented on manuscript drafts. All authors have approved the final manuscript.

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managers in everyday clinical practice. **Implications for Practice:** Service providers can use the guide to formulate intentions and make decisions with suggestions and priorities or as a reflexive tool for organizational improvement.

Background

Over the last decade there have been many attempts to improve quality and safety for patients in healthcare services; however, hospitals still report poor patient outcomes.[1,2] Next-of-kin and family caregivers are important collaborative partners in keeping patients safe both in hospitals and at home.[3–5] They are, however, seldom considered equal partners in the medical team around the patient despite taking on many important care tasks in different parts of the cancer care trajectory.[6–8] Consequently, next-of-kin may feel overburdened and stressed.[9–11] In hospital cancer care, there is no set standard associated with next-of-kin involvement in general treatment or in relation to improving cancer service quality and safety.[12] Next-of-kin involvement is seldom directly related to quality and safety, and research on this topic is rare.[12,13] Previous research has identified a need for tools and methods to guide the complex area of next-of-kin involvement in general and in relation to the context of the involvement (eg, cancer care, pediatrics, geriatric care, intensive care).[8,14,15] Such a development should incorporate a multistakeholder perspective that includes healthcare professionals, patients, and next-of-kin.[16] Our study therefore takes this perspective.

Consensus methods are widely used in healthcare research to aid decision making, problem solving and idea generation.[17–19] Consensus methods often gather experts in a field, such as oncologists or nurses to determine consensus on a given topic. There is, however, a lack of research on how to gather stakeholders across hospitals with a combined multidisciplinary, patient, and stakeholder perspective to arrive at a consensus on a topic from a group of representatives with diverse backgrounds and roles.[12] Some topics, such as how to guide next-of-kin involvement in cancer care, as in our study, requires a broad representation of stakeholders to incorporate different perspectives in a consensus process and reach an agreement on the way forward (in other words, to cocreate).[20,21]

Consensus methods have multifaceted challenges. There are many potential practical obstacles, such as funding, time, organization and geography, when establishing an arena for the sharing of ideas and learning.[18] Consequently, the method may fail without careful attention to the cocreation of knowledge between stakeholder groups and researchers.[22–24]

Aim and Research Questions

With this in mind, we invited stakeholder representatives from 2 Norwegian hospitals to join a panel where we used a modified nominal group technique (NGT).[25]

The overarching research problem for the panel was as follows: What topics and elements should be included in a next-of-kin involvement guide to support quality and safety in hospital cancer care?

The following research questions guided the consensus process:

1) What can we learn from next-of-kin experiences with hospital cancer care?
2) How can next-of-kin experiences be valued more systematically to improve the quality and safety of cancer care?
3) What methods or tools are appropriate for collecting experiences and for next-of-kin involvement locally, regionally, and nationally?

Based on the consensus technique, we developed a guide for use in hospital cancer care to increase the focus on involvement and take advantage of the experiences of cancer patients' next-of-kin. The aim of this article is to present the results from the consensus process and to produce a guide for next-of-kin involvement in hospital cancer care.

Study Design and Setting

This article is part of a mixed-method project with a convergent design.[26] The design consists of 3 substudies that explore quality and safety in hospital cancer care in 2 Norwegian university hospitals (Figure 1).

Substudy 1 was a qualitative mapping of next-of-kin involvement and involvement methods in cancer care services in the 2 hospitals. This was an in-depth study of managers' and hospital staffs' perspectives. The study resulted in 2 published articles.[8,27] Substudy 2 was a quantitative measurement of next-of-kin satisfaction with cancer care services in the 2 hospitals and resulted in 1 published article.[15] Substudy 3, reported here, is a consensus process (using the NGT) where we synthesized substudies 1 and 2 and presented the findings to stakeholders invited from the 2 hospitals. The participants agreed on the most appropriate elements and topics in next-of-kin involvement in hospitals.

The study setting consists of 2 Norwegian university hospitals with their affiliated oncology departments. Both hospitals are affiliated with the same Regional Health Authority. The hospitals differ in size, number of employees, and budget, but the cancer departments are approximately the same size and are subject to the same national and regional policy documents (see details in Table 1).

The Norwegian Healthcare Context

Taxes fund the Norwegian healthcare system. All residents are covered by the National Insurance Scheme. The system is built on universal access and free choice of providers. Norway's 4 Regional Health Authorities provide healthcare services within their district. The government has the financial oversight for all public hospitals.

Norway's cancer registry reported 34 190 new cancer cases in 2018 and 283 984 people living with cancer.[28] The incidence of cancer in Norway is higher than the average of the 36 Organisation for Economic Co-operation and Development countries

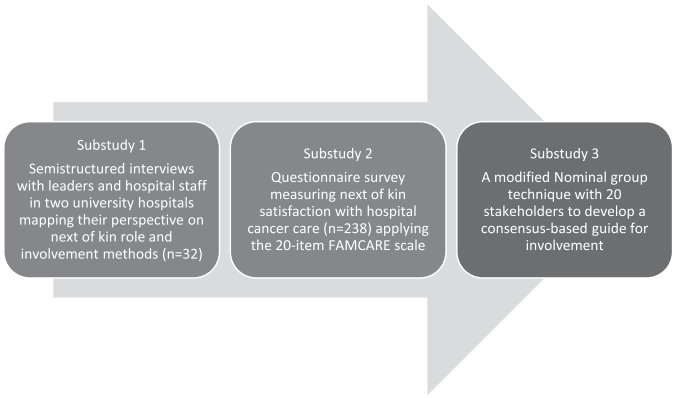

Figure 1 ■ Overview of the project.

(age-standardized rate ratio, 1.12), but the cancer mortality rate is lower (age-standardized rate ratio, 0.95).[29]

Under the Norwegian Patient and User Act (1999), the patient chooses the friend or family member who is the closest next- of-kin (§1.3b). The law does not specify any specific tasks or obligations for the next of kin in relation to the provision of healthcare services. The government has that responsibility in Norway; in other countries, there are stronger expectations that next of kin will take on a greater role in providing healthcare services.

Theoretical Approach

ORGANIZING FOR QUALITY

The theoretical backdrop of this research project (Figure 1) is the Organizing for Quality (OQ) model developed by Bate and colleagues.[30] The model focuses on 6 challenges that hospitals must meet (structural, political, cultural educational, emotional, physical and technological) as part of working on quality and safety in healthcare.[30(p169)] The OQ model was developed based on international studies in leading European and American hospitals.[30–32] It has also been tested and refined by studies in Norwegian hospitals.[33–35] We apply a theoretical model in our research project to obtain the guidance to understand and investigate quality and safety processes in hospitals with a multilevel apporach.[36,37] As a result of the first substudy (Figure 1), we suggested modifications to the OQ model. Figure 2 is built on the experience and views of leaders and healthcare professionals with next-of-kin involvement in the 2 hospitals. In Figure 2, we identified and elaborated on the 6 quality challenges and then added areas of key importance for next-of-kin involvement based on our findings to make it relevant for stakeholders in a clinical setting.[8] Figure 2 is operationalized in this article into the next-of-kin involvement guide (Figure 5).

■ Methods

The study design reported in this article is a consensus process inspired by the NGT. The NGT was developed by Delbecq and colleagues[25] in 1975 and comprises 4 key elements: silent generation, round robin, clarification, and voting. All 4 elements are keys to arriving at a general agreement on a particular topic. The NGT is often used to explore stakeholders' or consumers' views, but the method can be modified for other purposes.[18]

The modified NGT for this study was conducted in 3 phases to reach stakeholder agreement. Figure 3 is an overview of the process, consisting of preparation, consensus, and post-feedback, followed by validation of the results.

Characteristics of Participants

Purposive sampling was used to identify healthcare professionals and next-of-kin representatives.[38] Participation was voluntary and done in close collaboration with the 2 hospitals. Leaders from 7 inpatient and outpatient cancer care wards in the 2 hospitals participated

Table 1 • Local Context Descriptions With Key Figures

Local Context	Large City in Norway	Large City in Norway
Included hospitals	Hospital A	Hospital B
Size	University hospital Local hospital for 330 000 inhabitants	University hospital Local hospital for 420 000 inhabitants
Employees	7500	12 000
Budget	6.8 billion NOK	10.8 billion NOK
Cancer departments	Second largest regional cancer department with 2 cancer care wards, 2 outpatient clinics, and 1 radiotherapy unit	Main cancer department in the region with 2 cancer care wards, 1 outpatient clinic, and 1 radiotherapy unit

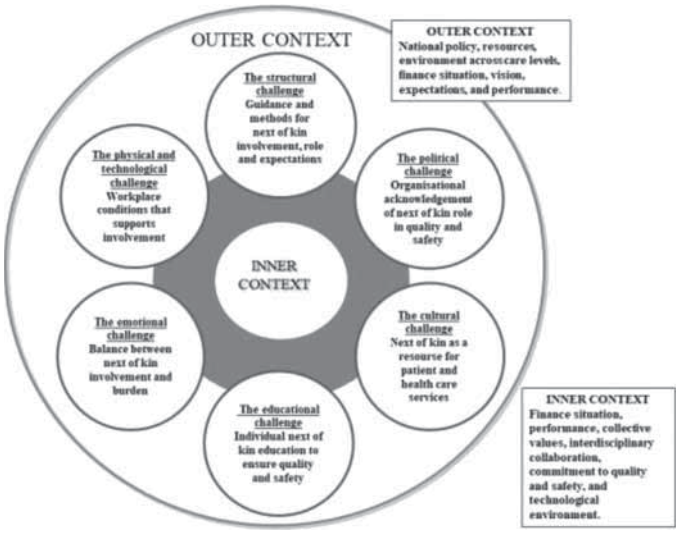

Figure 2 ■ Revised framework model inspired by Bate and colleagues.[8,30]

in the recruitment of participants, among whom were leaders and multidisciplinary hospital staff. IJB contacted 1 coping center in both regions. The center, a meeting point for cancer patients and their representatives, offers courses, networking opportunities, and informal conversations. The 2 centers were asked if they would participate with 1 representative in the meeting. They also made contact with a local next-of-kin representative who was able to participate. For the consensus meeting, the Regional Health Authority appointed a regional next-of-kin representative. This representative was the only person who received compensation for this meeting in line with Regional Health Authority guidelines. Table 2 lists the panel participants for this study.

Overview of the Modified NGT

A consensus method, based on a modified NGT, was applied as a single 1-day meeting with 20 participants (5 next-of-kin representatives, 10 oncology nurses, and 5 physicians) from the 2 Norwegian university hospitals. The consensus meeting was supervised by a 5-member research team: 4 moderators (SW, GSB, BG, and IJB) and 1 nonparticipant observer (BF) who collected qualitative data on the nominal group processes during the 1-day meeting. This is recommended by Jones and Hunter.[17] Observation notes were embedded in the analysis and used in the interpretation of the group process and results.

Analysis

The modified NGT developed for this study had 3 phases (Figure 3). The first phase was conducted by email, followed by a face-to-face meeting. The results were then emailed to the participants. The analysis process followed the 3 phases depicted in Figure 4.

PHASE 1: PREPARATION

In the first phase in the modified NGT, we had the participants engage in reading and reflective writing. One month before the meeting, we sent the participants 2 articles[8,27] that described the results from the larger mixed-method project of which the consensus process is a part. We also asked the participants to reflect individually upon the topic "What is the role of next-of-kin for quality and safety

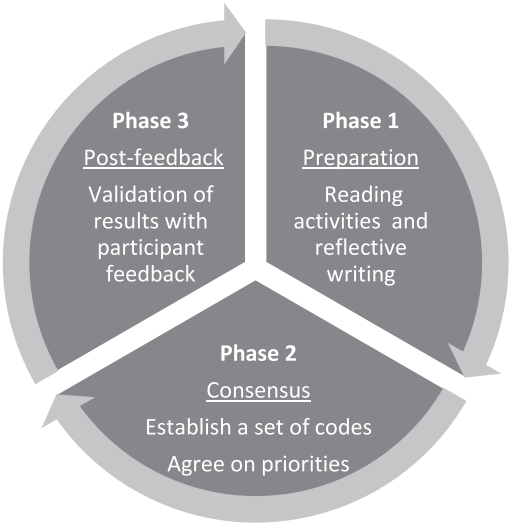

Figure 3 ■ Overview of the 3-phase nominal group technique.

Table 2 • Overview of Panel Participants

Participants in the Consensus Process	Number of Attendees
Local next-of-kin representatives	2
Regional next-of-kin representatives	1
Coping centers next-of-kin representatives	2
Hospital A—healthcare professionals	2 physicians and 6 oncology nurses
Hospital B—healthcare professionals	3 physicians and 7 oncology nurses
Gender of the participants	2 male and 18 female
Positions	5 managers and 15 healthcare professionals

in cancer care?" In addition, we asked them to respond in writing to the following questions that guided the consensus process:

1) What can we learn from next-of-kin experiences with hospital cancer care?
2) How can next-of-kin experiences be valued more systematically to improve cancer care quality and safety?
3) What methods or tools are appropriate for collecting experiences and for next-of-kin involvement (locally, regionally, nationally)?

The purpose of these assignments was to prepare each participant for the consensus process and to empower them to express themselves. Within 3 weeks, all the participants emailed a 1-page text to IJB with their thoughts and suggestions related to the research questions, earlier research findings, and their own experiences.

The research team led by IJB conducted a content analysis of the texts before the consensus meeting. The content analysis was inspired by Graneheim and colleagues.[39,40] The analysis consisted of a 3-step characterization of the participants' texts: (1) selecting meaning units, (2) condensing meaning units, and (3) defining subcategories and categories. The purpose of the content analysis was to identify categories and use these as an ice breaker to get all participants on the same page, before starting the consensus discussions in phase 2. An example of the content analysis can be found in Table 3.

PHASE 2: CONSENSUS

The consensus meeting took place on a neutral arena that had no affiliation with any of the hospitals. Half of the participants had to travel by plane to attend the meeting in the city of one of the case hospitals. The meeting agenda is provided in the Appendix. The meeting started with a presentation by the participants, followed by a short introduction to the NGT and a summary of the results of previous substudies, and concluded with an overview of the content analysis on the emailed text from the participants. The participants learned about the views of leaders and healthcare professionals on next-of-kin involvement, the survey results from next-of-kin in the 2 hospitals, and the content analysis based on their initial reflections about these findings.

GROUP CONSENSUS—ESTABLISHING A COMMON SET OF CODES. After the introduction, we split the 20 participants into 2 groups to create a reflexive discussion, share experiences, generate new ideas, and establish a set of codes that the group could agree on for presentation in the following plenary session. Discussion questions were assigned for the first group session. Group 1 discussed these questions: What can we learn from next-of-kin experiences with hospital cancer care? How can next-of-kin experiences be valued more systematically to improve cancer care quality and safety? Group 2 discussed the question: What methods or tools are appropriate for collecting experiences for next-of-kin involvement (locally, regionally, nationally)? The 2 groups engaged in a consensus process led by moderators. The process was based on a reflexive discussion in which all suggestions were written on flip sheets, continued by a round-robin process until there were no more suggestions to discuss. Then the group and the moderators coded the suggestions by sorting and identifying common topics and suggestions. When the group reached consensus by agreeing on the codes, this session ended.

PLENARY CONSENSUS—AGREEING ON THE TOP 5 PRIORITIES. After the group sessions, we reunited the 2 groups in a plenary session. In the plenary session, all participants reached agreement on the codes set by the 2 smaller groups. The participants also completed an anonymous poll of the 5 initiatives that hospital cancer care services should prioritize when working on

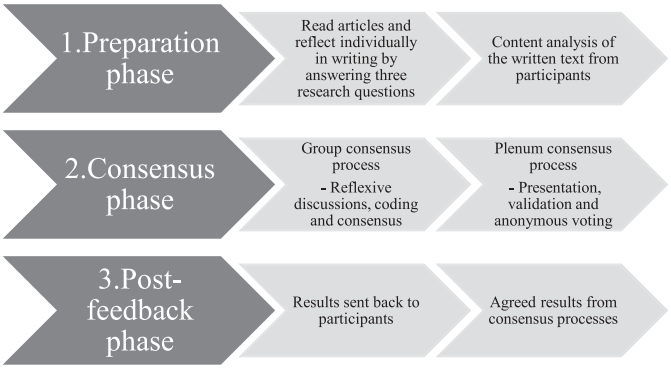

Figure 4 ■ The modified nominal group technique.

Table 3 • Example of the Content Analysis

Selecting Meaning Units	Condensing Meaning Units	Defining Subcategories	Defining Categories
"Next-of-kin experiences that are expressed can contribute to increased quality of healthcare. My experience is that collaboration with the next-of-kin in care and treatment of the cancer patient provides increased security in the patient's coping with cancer and its treatment."	Next-of-kin experiences can contribute to increased quality of healthcare. Collaboration with next-of-kin provides increased security in the patient's coping with the disease and treatment.	Next-of-kin involvement is important for how well the patient is coping with disease and treatment.	Involvement of next-of-kin is important for coping with disease and treatment.

next-of-kin involvement. The plenary session was divided into 2 parts, with a plenary consensus process for each group's research question. Each group presented the codes to the other and then discussed whether additional codes were needed. After the total group had reached agreement on the codes, we conducted anonymous voting on the 5 most important codes. Each participant manually submitted the votes to the research team. Both plenary consensus processes were completed in the same manner.

PHASE 3: POST-FEEDBACK

One week after the meeting, the participants received an email with the results of the anonymous voting session. We invited them to comment on the results. Only 1 participant responded, suggesting that we change the phrase "objective information" in priority 5 (Table 6) to "concrete information." We embedded the revised wording in the code.

Table 4 • Overview of Codes From Consensus 1: "What Can We Learn and How Can We Value"

Codes
Important for evaluating aid
Provides healthcare professionals with more objective or concrete information on the patient
Crucial for how well the patient handles the illness and treatment through the cancer care trajectory
Reveals areas where the help provided is not good enough
Next-of-kin who observe and interpret what happens to the patient are important, and they need to be trained in basic skills
Important throughout the cancer care trajectory. Next-of-kin have an eye for "the whole life"
Next-of-kin that are secure in their role can contribute to patient safety
Poor continuity of healthcare professionals creates unsafe next-of-kin
Healthcare professionals need more knowledge of next-of-kin involvement
Acknowledge the next-of-kin role as a coordination role that needs to be adjusted to individual needs
Next-of-kin experiences should be documented and systematized (user surveys, "heart sigh" book, next-of-kin notice in the documentation system)
Coherence between service levels (hospital and municipalities) with support from volunteer organizations
Be aware of those patients who do not have a next-of-kin
System improvement that uses next-of-kin evaluation as a measure (user surveys)
Double loop learning with respond to service users

■ Results

In the following, we present the results from the consensus meeting. Tables 4 and 5 show the codes from the group sessions, and Tables 6 and 7, the codes from the plenary session. We have incorporated the nonparticipant observers' notes into the results presentation.

Group Consensus Results

GROUP CONSENSUS 1: "WHAT CAN WE LEARN AND HOW CAN WE VALUE NEXT-OF-KIN INVOLVEMENT?"

Table 4 summarizes the codes from the group discussion process in response to the questions: What can we learn from next-of-kin experiences with hospital cancer care? How can next-of-kin experiences be valued more systematically to improve the quality and safety of cancer care? There was a good atmosphere in this group. According to the nonparticipant observers' notes, all the participants were engaged in contributing to the process. The next-of-kin

Table 5 • Overview of Codes From Consensus 2: "Methods and Tools for Collecting Experiences"

Codes
Technology (apps, documentation, admission forms)
Economy (travel expenses, time off work, consultations, diagnose related groups' effort-based funding, social rights as a next-of-kin)
Involvement in patient care (clarification of roles, different phases of the trajectory (curative or palliative), standardization of involvement in different parts of the trajectory, documentation)
Needs clarification/information in the summon letter and in different phases (expectations, resources, wishes and needs, information in summon letter and different phases, checklist on needs at discharge, information)
Interaction (learning and coping centers in the municipalities)
Information (to next-of-kin, learning and coping)
Training of healthcare professionals (ethics, how, methods)
One appointed healthcare professional for the next-of-kin
User participation with special focus on the next-of-kin perspective

Table 6 • Top 5 Priorities Consensus 1: "What Can We Learn and How Can We Value?"

What can we learn from next-of-kin experiences with hospital cancer care? How can next-of-kin experiences be valued more systematically to improve the quality and safety of cancer care?
1 Next-of-kin experiences should be documented and systematized (user surveys, "heart sigh" book, next-of-kin notice in the documentation system).
2 Next-of-kin who are secure in their role can contribute to patient safety.
3 System improvement that uses next-of-kin evaluation as a measure (user surveys).
4 Reveals areas where the help provided is not good enough.
5 Important for evaluating aid.
5 Provides healthcare professionals with more objective or concrete information on the patient.
5 Crucial for how well the patient handles the illness and treatment through the cancer care trajectory.
5 Next-of-kin who observe and interpret what happens to the patient are important, and they need to be trained in basic skills.

representatives were courageous and added important input. The physicians were initially a little reticent, but according to the observation notes, all participants were seen by the moderators in this group. The results acknowledged the next-of-kin's central role in patient care as the most important learning dimension for next-of-kin involvement. Participants highlighted that next-of-kin possess essential information about the patient, are central to care coordination, and give valuable feedback about how patients respond to the treatment.

GROUP CONSENSUS 2: METHODS AND TOOLS FOR COLLECTING EXPERIENCES

Table 5 gives an overview of the codes from the group discussion process with respect to this question: What methods or tools are appropriate for collecting experiences and for involvement of next-of-kin (locally, regionally, nationally)?

According to the nonparticipant observer's notes, there was very good participation and engagement in this group. Moreover, all participants were seen by the moderators in this group, and the group progressed with the help of the moderators. The group seemed to struggle with coding the discussion moments and needed the moderators' assistance. Engagement declined slightly in the coding phase. However, the group members remained engaged and shared their views on the topic of the session. The results focused on standardization of involvement in different parts of the cancer care trajectory as the most important tools and methods to integrate into a guide. They suggested use of apps, a checklist, and the medical record document and improve involvement.

Plenary Consensus Results

AGREEING ON TOP 5 PRIORITIES

Tables 6 and 7 give an overview of the results of the anonymous voting on the 2 top 5 priorities for hospitals' cancer care services to address. The top 5 priorities are meant for service development use to support next-of-kin involvement in cancer care, especially in relation to (1) learning and information and (2) recommendation of methods to promote involvement in practice.

According to the nonparticipant observer's notes, there was less engagement in the plenary process than in the 2 previous separate group discussions. Even if it was a more challenging plenary process, it generated discussion and new insights.

Evaluation of the Method and the Meeting

At the end of the day, an evaluation session allowed the participants to share their views on the consensus meeting. The group said that it had been very useful for them to have come to the meeting prepared. The group highlighted that the meeting had been a good arena to explore and discuss next-of-kin involvement. They also noted that they felt safe sharing their opinions and speaking their minds. One next-of-kin representative thought that the inclusion of more next-of-kin representatives in the meeting could have contributed more input.

■ Discussion

Developing Key Concepts for Next-of-Kin Involvement in Hospital Cancer Care

In this article, we presented the results from a consensus process with the purpose of identifying key topics and elements that should be included in a next-of-kin involvement guide for quality and safety in hospital cancer care. The purpose of the process was to describe and suggest changes for next-of-kin involvement practice in hospital cancer care, but it can also be relevant for other healthcare services or decision-making support bodies. The top 5 priorities in this study show that next-of-kin are considered key stakeholders in keeping the patient safe. The stakeholder groups emphasized that, first, it is important for cancer care services to start developing systems for the systematization and documentation of next-of-kin experiences for further use. An example could be by integrating data on next-of-kin experiences, for instance, in user surveys.[15]

Second, the panel agreed that hospital cancer care needs to recognize and change service in a direction that formally integrates and uses next-of-kin experiences in service improvement

Table 7 • Top 5 Priorities in Consensus 2: "Methods and Tools for Collecting Experiences"

What methods or tools are appropriate for collecting experiences and for involvement of next-of-kin (locally, regionally, nationally)?
1 Involvement in patient care (clarification of roles, different phases of the trajectory [curative or palliative], standardization of involvement in different parts of the trajectory, documentation)
2 Interaction (learning and coping centers in the municipalities)
3 Information (to next-of-kin, learning and coping centers)
4 Training of healthcare professionals (ethics, how, methods)
5 Technology (apps, documentation, admission forms)

at the micro level. Moreover, there was consensus in terms of personalized next-of-kin training and support to prepare them for the challenges and care tasks that they will perform. There was agreement that treating next-of-kin as an equal part of the patient's medical care team is a prerequisite for sound next-of-kin involvement. Our findings are in line with other studies highlighting next-of-kin as an underused resource, for evaluating aid and providing healthcare professionals with more objective information on the patient's condition.[12,13,41–45]

Another important message from our consensus process is that hospital cancer care should become more aware of how to use next-of-kin experiences because of its potential impact on how well the patient handles treatment and care. In other words, next-of-kin involvement in cancer care is important for patient outcome and should be a higher priority in future practice. This message echoes other studies that highlighted the important role of next-of-kin involvement in healthcare.[5,6,10,13,44,45]

Organizing for Quality and Safety: A Next-of-Kin Involvement Guide

There is a constant call for theory development in research and for incorporating theory into everyday practice in healthcare organizations.[46] Our project responds to this call and builds on Bate and colleagues'[8,30] conceptualization of quality and safety in healthcare. The project is also in line with experience-based co-design[47] by combining participatory design and user experiences in developing a guide to improve cancer care services. Co-design in this study has required the participation of multidisciplinary healthcare professionals within cancer care and next-of-kin representatives from 2 university hospitals to share and reflect on their experiences to identify priorities for implementation of change.[48,49]

As previously mentioned, we apply the OQ as our theoretical backdrop, which we have modified to fit next-of-kin involvement in cancer care (see Figure 2). We will now present the next-of-kin involvement guide (Figure 5) that encompasses, develops and operationalizes Figure 2 with the results from the consensus process. We want to give the model (Figure 2) a broader empirical foundation, one that incorporates a multistakeholder approach. The main purpose is, however, to convert the model into a practical tool with direct connection to both theory and knowledge-based adaptations derived from stakeholder involvement and the consensus process. Until now, this has been lacking in the research literature.[19–21,50]

Figure 5 illustrates the next-of-kin involvement guide. The guide is a result of merging the framework model (Figure 2) and the results from the consensus process (Tables 4 and 5). Through this merger, we have developed a guidance tool for hospital cancer care services by translating theory into practice with suggestions on where to start making changes to explore and support next-of-kin involvement. The stakeholder groups agreed on top 5 priorities in each of the 2 consensus sessions. These priorities are bolded in the figure; however, the stakeholder groups did not state that the additional codes had a lower priority. Therefore, we embedded all suggestions in the figure and grouped them under the 6 quality challenges.

The guide can be used in either as a guide with suggestions and priorities or as a reflexive tool for improvement efforts in the organization. The latter approach has been adapted and explored with the OQ model,[31,51] in the Norwegian primary care context,[37,52] and in international studies.[53–55]

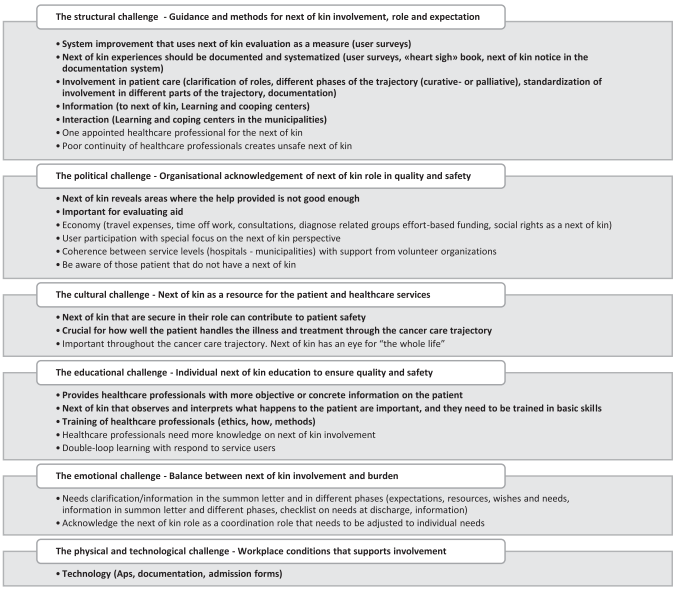

Figure 5 ■ Organizing for quality and safety: a next-of-kin involvement guide.

Implications for Practice, Research and Education

Next-of-kin involvement in healthcare services is complex. Like Bell and colleagues,[16] we contend that decision and actions within this area should be based on a multistakeholder approach where the perspectives of all stakeholders are heard and integrated. This study adds to the knowledge of how to create an arena for hospitals to share ideas and learn from each other and from involved next-of-kin stakeholders. The reflexive space established through the consensus process presented in this article brings attention to practical values and challenges of next-of-kin involvement, which can inform everyday practice in hospitals. A key rationale for reflexive practice is bringing together stakeholders with the ability to engage in the cocreation of knowledge that supports organizational learning to reach a higher level of understanding.[14,56–58] This study explains how the consensus method can be used for different purposes in hospitals, such as the development of internal guidelines, evaluation of performance, change management, interventions, compliance, and communication between disciplines or institutions.

At the same time, there is potential to identify priority topics for research and practice improvement by using consensus methods. This has been demonstrated in other studies[59,60] that have set research priorities with the use of a consensus design. For educational purposes, the methodological approach can target future strategic directions with input from stakeholders involved in the specific areas or questions of interest such as cancer care, diabetes, and pediatrics. However, how successful this translation of knowledge and learning turns out to be, depends on how healthcare professionals value research, develop knowledge and use this proactively for innovation.[61]

Further studies and practical testing of the next-of-kin involvement guide are needed. Future evaluations should focus on how relevant and applicable the guide (Figure 5) is perceived by the hospitals and the clinical staff and how they respond to and modify their practice accordingly.[50,62]

We envision future testing of the guide for diverse purposes. Nursing staff on cancer wards could use it to reflect on current practice and discuss potential changes. It could also be tested in multidisciplinary teams of nurses, doctors, and managers in cancer care departments to assess structures, culture, and methods in use and what could be changed to strengthen next-of-kin involvement. We envision, for example, dialogue cafes in which patients, next-of-kin, and healthcare professionals use the guide as a basis of discussion.

Strengths and Limitations

This study has both strengths and limitations. First, the consensus meeting was a face-to-face 1-day meeting. Because of the extensive consensus processes, this meeting could have benefited from being extended by 1 day. However, funding constraints made this impossible. All participants from one of the hospitals had to travel by plane for this meeting, and a 1-day extension would have increased the cost and kept healthcare professionals out of clinical work for an additional day. Consequently, recruiting healthcare professionals for a 2-day meeting would have been more difficult.

A second limitation was sample size and representativeness of care providers. Healthcare professionals were the largest group in the interdiciplinary team of care providers, and an increased number of user representatives might have produced an even better understanding of the 6 challenges mentioned in the involvement guide. We mixed the groups with healthcare professionals and next-of-kin representatives to try to create consensus across diciplines and stakeholder groups with potentially different perspectives. This was done in line with the multistakeholder approach in this study. We have tried our best to meet ethical standards by having each participant prepare for the meeting by reading, reflecting and writing; to engage in the meeting through the introduction of research results and content analysis; by engaging a nonparticipant observer (observing power in the groups); and by asking the moderators to be aware of the potential risk of uneven power relations in the groups. However, we cannot rule out the potential of participants who did not dare to speak up in the mixed groups.

Third, there is a possibility that asking the participants to read and reflect on earlier published papers might have affected their views on the topic and could, in that sense, be a limitation. However, this could also be one of the study's strengths. This is a key step in the modified NGT (Figure 4) and a way to retrieve and embed feedback to ensure stakeholder involvement in the research project.

■ Conclusions

In this article, we have described a nominal group consensus technique conducted with representatives from cancer departments in 2 Norwegian university hospitals. We included next-of-kin representatives and healthcare professionals within hospital cancer care. During the process, they identified key topics and elements in next-of-kin involvement. Based on the results, we developed a guide for next-of-kin involvement in cancer care. The guide (Figure 4) is created to support hospitals and has the potential to increase attention to and overcome challenges in next-of-kin involvement. Moreover, it emphasizes the role of next-of-kin and their importance for quality and safety in cancer care. Service providers can use the guide to develop and improve next-of-kin involvement practice or as a reflexive tool for organizational improvement. However, for future research, the guide needs additional empirical testing and refinement.

ACKNOWLEDGMENT

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Appendix• Agenda of the meeting.

08:30-09:00 AM	Registration
09:00-10:10 AM	Introduction
10:10-10:30 AM	Break
10:30 AM-12:00 noon	Group process (2 groups)
12:00 noon-1:00 PM	Lunch
1:00-2:15 PM	Plenary process 1
2:15-2:35 PM	Break
2:35-3:40 PM	Plenary process 2
3:40-4:00 PM	Summary

Appendices

Appendix 1

Approval from REK 18.08.15

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad	55978499	05.10.2015	2015/1488/REK vest
			Deres dato:	
			18.08.2015	

Vår referanse må oppgis ved alle henvendelser

Inger Johanne Bergerød
Avdeling for blod og kreftsykdommer

2015/1488 Pårørendes rolle og betydning i arbeidet med kvalitet og sikkerhet innen kreftfeltet på sykehus

Forskningsansvarlig: Helse Stavanger HF
Prosjektleder: Inger Johanne Bergerød

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 17.09.2015. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektomtale
Formålet med prosjektet er å undersøke de pårørendes rolle og betydning i arbeidet med kvalitet og sikkerhet når det gjelder kreftomsorg på sykehus. Prosjektet vil kunne bidra til ny kunnskap om a) ledelsen og helsepersonells oppfatninger om pårørendes rolle b) pårørendes tilfredshet og erfaringer c) de beste og riktigste metodene å involvere pårørende i pasientsikkerhetsforbedring. Prosjektet inkluderer kvalitativ kartlegging av involvering av pårørende og av pårørendes fornøydhet og erfaringer.

Vurdering
Fremleggingsvurdering
Helseforskningsloven gjelder for medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger, jf. § 2. Slik forskning defineres som virksomhet som har til hensikt å skaffe til veie n kunnskap om helse og sykdom, jf. § 4 bokstav a. Etter en kort diskusjon konkluderte komiteen med at deler av studien (studie 2) har som formål å søke ny kunnskap om sykdom og helse. Studien som helhet vil derfor bli behandlet etter helseforskningsloven.

Søknad og forskningsprotokoll
omiteen har ingen innvendinger til søknaden eller forskingsprotokollen.

Rekruttering
Søknaden legger opp til at deltakerne i studie 2 (pårørende) vil bli rekruttert gjennom ansatte på avdelingsnivå. Komiteen ber isteden om at de pårørende rekrutteres via pasienten slik at også pasienten er informert om studien.

Informasjonsskriv til de pårørende
REK har noen mindre merknader til informasjonsskrivet. Overskriften i informasjonsskrivet må endres slik at den norske prosjekttittelen fremgår. Skrivet må også opplyse om at koblingsnøkkel og navnelister lagres i tre år etter prosjektslutt, før opplysningene anonymiseres. Setningen «*Vi vil med dette få invitere deg til å delta*» bør byttes ut med «*Vi ønsker å spørre deg om du vil delta*».

Prosjektslutt
Prosjektslutt er opp gitt å være 01.01.21. Lydfiler vil bli slettet straks de er transkriberte. Det resterende datamaterialet vil bli oppbevart i tre år etter prosjektslutt. Komiteen har ingen innvendinger til dette.

Vilkår

- Studien må rekruttere de pårørende via pasienten.
- Informasjonsskrivet må revideres.

Vedtak
REK vest godkjenner prosjektet på betingelse av at ovennevnte vilkår tas til følge.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 01.07.2021 jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Ansgar Berg
Prof. Dr.med
Komiteleder

Camilla Gjerstad
rådgiver

Kopi til: forskning@sus.no

Appendix 2

Approval from REK change 21.10.15

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Øyvind Straume	55978496	29.10.2015	2015/1488/REK vest
			Deres dato:	Deres referanse:
			21.10.2015	

Vår referanse må oppgis ved alle henvendelser

Inger Johanne Bergerød

2015/1488 Pårørendes rolle og betydning i arbeidet med kvalitet og sikkerhet innen kreftfeltet på sykehus

Forskningsansvarlig: Helse Stavanger HF
Prosjektleder: Inger Johanne Bergerød

Vi viser til søknad om prosjektendring datert 21.10.2015 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet ved REK vest på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

Ønsket prosjektendring
Prosjektendringen innebærer et revidert informasjonsskriv, i tråd med REK sin anbefaling.

REK vest ved sekretariatet vurderte saken.

Vurdering
REK vest har ingen innvendinger til ønsket endring.

Vedtak
REK vest godkjenner prosjektendringen i samsvar med forelagt søknad.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Øyvind Straume
sekretariatsleder

Kopi til: *forskning@sus.no*

Besøksadresse:
Armauer Hansens Hus (AHH),
Tverrfløy Nord, 2 etasje. Rom
281. Haukelandsveien 28

Telefon: 55975000
E-post: rek-vest@uib.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK vest, not to individual staff

Appendix 3

Approval from REK change 03.10.16

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Øyvind Straume	55978497	10.10.2016	2015/1488/REK vest
			Deres dato:	Deres referanse:
			03.10.2016	

Vår referanse må oppgis ved alle henvendelser

Inger Johanne Bergerød
Avdeling for blod og kreftsykdommer

2015/1488 Pårørendes rolle og betydning i arbeidet med kvalitet og sikkerhet innen kreftfeltet på sykehus

Forskningsansvarlig: Helse Stavanger HF
Prosjektleder: Inger Johanne Bergerød

Vi viser til søknad om prosjektendring datert 03.10.2016 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet ved REK vest på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

Ønsket endring
Prosjektendringen innebærer en økning i antall deltakere, en vil i tilbudet om deltakelse til 300 informanter fra hvert av sykehusene. Videre er spørreskjemaet endret. Prosjektendringen innebærer også at å besvare spørreundersøkelsen vil være tilstrekkelig samtykke for den som fyller ut (den pårørende).

REK vest ved sekretariatet vurderte saken.

Vurdering
REK vest har ingen innvendinger til at spørreskjemaet er tilstrekkelig som samtykke fra den som fyller ut, eller til økning i antall forskningdeltakere. Vi merker oss at rekrutteringen gjøres via pasienten, og har ingen innvendinger til forelagt plan for inklusjon.

Vedtak
REK vest godkjenner prosjektendringen i samsvar med forelagt søknad.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Øyvind Straume
seniorkonsulent

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Appendix 4

Approval from the hospitals

HELSE BERGEN
Haukeland universitetssykehus

Personvernombudet

Birte Fagerdal/lokal koordinator HUS
Haukeland universitetssykehus/ Avdeling for kreftbehandling og medisinsk fysikk
birte.fagerdal@helse-bergen.no

Deres ref:	Vår ref:	Saksbehandler	Bergen,
	2016/639/	Christer Kleppe, tlf. 55975558	18.01.2016

Pårørendes rolle og betydning for kvalitet og sikkerhet innen kreftfeltet på norske sykehus

Viser til innsendt melding om behandling av personopplysninger / helseopplysninger. Det følgende er en formell tilråding fra personvernombudet. Forutsetningene nedenfor må være oppfylt før innsamlingen av opplysningene / databehandlingen kan begynne.

Som del av en studie skal det gjennomføres en spørreundersøkelse blant pasienters pårørende, ansatte ved avdelingen og ledere. Spørreundersøkelsen er frivillig, og det innhentes samtykke fra deltakerne. Pårørende som samtykker fyller ut et spørreskjema. Svar på spørreskjemaet skal utleveres avidentifisert til Helse Stavanger HF fra avdelingen på Haukeland Sykehus.

Det skal også behandles opplysninger om ansatte i foretaket og ledere på avdelingene. Det er utformet et eget samtykke for denne delen av studien. Opplysninger skal samles inn gjennom delvis strukturerte intervjuer som tas opp på bånd.

Studien er godkjent av REK (2015/1488).

Personvernombudet har vurdert det til at den planlagte databehandlingen omfatter behandling av helse- og personopplysninger til ekstern virksomhet, og er meldepliktig til personvernombudet i henhold til personopplysningsloven § 33 og personopplysningsforskriften § 7-27.

Personvernombudet tilrår at utleveringen kan gjennomføres under forutsetning av følgende:

1. Prosjektet er forelagt avdelings-/klinikkdirektør som har godkjent at prosjektet kan gjennomføres ved avdelingen.
2. Det skal ikke behandles opplysninger om tredjeperson.
3. **Intervjuobjektene skal informeres tydelig forut for og under intervjuet om at de må avstå fra å omtale identifiserbare tredjepersoner og om at unnlatelse av å gjøre dette kan medføre brudd på taushetsplikten.**
4. Svarskjema fra pårørende samles inn og avidentifiseres lokalt på sykehuset før de utleveres til Helse Stavanger HF.
5. Behandling av helse- og personopplysningene skjer i samsvar med og innenfor det formål som er oppgitt i meldingen.
6. Utleveringen må være godkjent av klinikk-/avdelingsdirektør.

7. Tilgangen til opplysningene skjer i overensstemmelse med taushetspliktbestemmelsene.
8. Utleveringen må skje på godkjent måte.
9. Dersom opplysningene som utleveres også skal lagres lokalt, skal de lagres avidentifisert på helseforetakets Kvalitetsserver. For å få tildelt plass på Kvalitetsserveren må saksnummer på denne godkjenningen (under Vår ref) fylles ut i søknadsskjemaet og selve tilrådingsbrevet må også legges ved. Søknadsskjema finnes på:
   Helse Bergen Innsiden - Personvernombudet for Helse Bergen
   Annen elektronisk lagringsform forutsetter gjennomføring av en risikovurdering som må godkjennes av foretakets IKT-sikkerhetsleder/personvernombud.
10. Kryssliste som kobler avidentifiserte data med personopplysninger lagres enten elektronisk på tildelt område på Kvalitetsserveren..
11. Data slettes eller anonymiseres (ved at krysslisten slettes) ved prosjektslutt 01.01.2021. Når formålet med databehandlingen er oppfylt sendes melding om bekreftet sletting til personvernombudet.
12. Dersom databehandlingen varer lengre enn 3 år, skal kontaktperson for prosjektet hvert tredje år sende personvernombudet ny melding som bekrefter at databehandlingen skjer i overensstemmelse med opprinnelig formål og helseforskningslovens regler.
13. Dersom formålet med databehandlingen endres, må personvernombudet informeres om dette.

Vennlig hilsen

Christer Kleppe

Christer Kleppe
Personvernombud

Kopi til:
Olav Mella

Besøksadresse: Jonas Liesv 65, 5021 Bergen
Postadresse: Helse Bergen HF, Postboks 1400, 5021 Bergen
Telefon: 05300 – Telefaks: 55976088 – E-post: postmottak@helse-bergen.no – Org. nr.: 983974724

Inger Johanne Bergerød

Fra: Bergerød, Inger Johanne <inger.johanne.bergerod@sus.no>
Sendt: 9. november 2016 10:13
Til: Inger Johanne Bergerød
Emne: Godkjenning av prosjektendring ID 529

Fra: Viste, Margot
Sendt: 14. oktober 2016 09:34
Til: Bergerød, Inger Johanne
Emne: SV: Godkjenning av prosjektendring ID 529

Forskningsavdelingen takker for oppdateringen og tar dette til orientering.

På vegne av
Forskningsavdelingen

Margot Viste
Sekretær
5151 3770/9902 1995

PB 8100, 4068 Stavanger
www.sus.no
Helse Stavanger

Fra: Bergerød, Inger Johanne
Sendt: 11. oktober 2016 12:03
Til: Lode, Kirsten; Viste, Margot
Emne: Godkjenning av prosjektendring ID 529

Ref PhD prosjekt « Improving the quality and safety of cancer care: a study of next of kin involvement» ID529.

'eg oversender godkjenning av prosjektendring av 03.10.16 til registering. Sender også med nye vedlegg som er godkjent av REK. Hvis det endringer dere mener personvernombudet ved SUS bør gjennomgå på nytt så gi beskjed. Vi planlegger ellers oppstart så fort som mulig neste uke hvis det ikke er noen innvendinger til det.

Vennlig hilsen

Inger Johanne Bergerød
Kreftsykepleier/Stipendiat ABK
Stavanger Universitetssykehus
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97753404
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HELSE STAVANGER

HELSE STAVANGER
Stavanger universitetssjukehus
Forskningsavdelingen

Notat

Til:
Inger Johanne Bergerød

Fra:
Forskningssjef Inger Økland

Kopimottakere:
Divisjonsdirektør Svein Skeie, Juridisk rådgiver Ina Trane

Dato: 03.11.2015
Arkivref: 2015/10158 - 106662/2015

Godkjent forskningsprosjekt - ID529

Forskningsprosjektet: «Pårørendes rolle og betydning i arbeidet med kvalitet og pasientsikkerhet i kreftomsorgen på norske sykehus.»

Det vises til søknad vedrørende oppstart av ovennevnte forskningsprosjekt. Prosjektet har vært vurdert av forskningsansvarlig og prosjektet er registrert i vår database med referanse: ID529. Vi ber om at vår referanse oppgis ved alle henvendelser.

Nødvendige tillatelser foreligger. Basert på disse og forskningsprotokoll godkjennes oppstart av prosjektet.

Forskningsavdelingen ønsker å minne om at:

- prosjektet må gjennomføres i henhold til protokollen og ved endringer må endringsmelding sendes
- dersom prosjektet er godkjent av REK, må søknad og godkjennelse av REK følges
- foreligger det godkjennelse fra Personvernombud må likeledes denne følges
- behandling av helse- og personopplysninger skjer i samråd med og innenfor det formål som er beskrevet
- ved tilgang til registre, skjer dette i overensstemmelse med taushetspliktbestemmelsene
- data lagres avidentifisert og evt. koblingsnøkkel lagres separat på helseforetakets forsknings/kvalitetsserver etter de regler som gjelder for bruk av denne
- dersom innhenting av pasientopplysninger baserer seg på samtykke, må samtykkeskjemaene oppbevares i låsbart skap
- data skal slettes eller anonymiseres ved prosjektslutt

Dersom prosjektet ikke starter og/eller blir avbrutt må melding sendes til Forskningsavdelingen. Likeledes sendes en kort sluttrapport.

Forskningsavdelingen ønsker lykke til med gjennomføring av prosjektet.

Appendix 5

Interview guide managers

Intervjuguide
Studie 1:Ledere

Improving the quality and safety in hospital cancer care: A study of next-of-kin involvement

Finansiert av Stavanger Universitetssykehus

Takk for at du tok deg tid til å delta i dette forskningsprosjektet. Målsetningen med denne studien er å finne ny kunnskap om pårørendes rolle, betydning og involvering i kvalitet og pasientsikkerhetsforbedring i kreftomsorgen på to norske sykehus. Resultatene vil være med på å gi helsetjenesten ny kunnskap om hvordan pårørende kan inkluderes i det systematiske arbeidet for å forbedre kvalitets- og pasientsikkerhet i kreftomsorgen på norske sykehus. Prosjektet skal resultere i en sjekkliste eller veileder for involvering av pårørende i kvalitet og pasientsikkerhetsforbedring.

Hensikten med dette intervjuet, og andre intervjuer vi gjør med ledere og helsepersonell på to sykehus er å undersøke hvordan organisasjonen jobber med kvalitet og pasientsikkerhetsforbedring og hvordan ledere og helsepersonell ser på pårørendes rolle i dette arbeidet. Hensikten er også å undersøke om intensjoner og praksis samsvarer, finne de beste metodene for involvering av pårørende i kvalitets- og pasientsikkerhetsforbedring og lære av gode strategier på tvers av sykehus innad i en helseregion.

Svarene dine blir ikke delt med noen utenfor forskningstemaet eller med andre av sykehusets ansatte. Intervjuene vil bli tatt opp på bånd og anonymiseres. Denne og andre samtaler blir transkribert og analysert av et forskerteam fra Universitetet i Stavanger og Stavanger Universitetssykehus. Alle data blir lagret på godkjent måte. Studien er godkjent av Regional etisk komité (prosjektnummer…) og av [personvernombud, sykehus].
(Pause til spørsmål og kommentarer. Kontroller at samtykkeskjemaet er lest, forstått og underskrevet. Hvis intervjuobjekt ønsker å gå videre settes opptakeren på.)

Innledningsspørsmål

a) Hvor lenge har du jobbet i denne organisasjonen?
b) Hva er din rolle her og hvor lenge har du hatt den rollen?
c) Hva er ditt ansvarsområde/din rolle når det gjelder kvalitets- og pasientsikkerhetsforbedring? (rolle knyttet til klinisk effektivitet, trygghet og sikkerhet i behandling og pleie, og pasienterfaringer)

Generelt om sykehuset

a) Skiller dette sykehuset seg fra andre du har arbeidet i med tanke på kvalitet og pasientsikkerhet? Nevn eksempler.
b) Er det andre faktorer som for eksempel prioritering, reorganisering, sammenslåing, nedskjæringer, nye reguleringer/lovendringer som har hatt en særlig positiv/ negativ innvirkning på kvalitet og pasientsikkerhetsforbedring og opprettholdelse?
c) Hvordan organiseres kvalitets- og pasientsikkerhetsprosjekter/ arbeid her?
d) Hva eller hvem er drivkraften bak slike prosjekter/arbeid?
e) Hvilke støtteenheter, funksjoner eller nøkkelpersoner finnes i organisasjonen?
f) Hvordan ivaretar denne enheten eller sykehuset brukerinvolvering relatert til kreftpasienter? Hvordan ivaretar og inkluderes pårørende erfaringer?

Kvalitetsstrategi/ pasientsikkerhet i praksis

a) Hvordan er arbeidet med kvalitet og sikkerhet organisert ved denne enheten/avdeling? (strategi, føringer og forventninger fra eier)
b) Hvem har det største ansvaret mener du for arbeidet med kvalitet og sikkerhet?
c) Hvilke forventninger har pårørende til denne enheten og til kreftomsorgen generelt?
d) Hvilke forventninger har helsepersonell til pårørende innen kreftomsorgen?
e) Hvilke metoder har dere for å involvere pårørende i behandling og pleie?
f) Hvilke metoder har dere for å involvere pårørende til forbedring av kreftomsorg og behandlingen til pasienten?
g) Hvordan samles pårørende erfaringer? (jmf ik-4-e)
h) Hvordan anvendes disse til forbedring?

Pårørendes rolle i kreftbehandlingen

a) Hvilken rolle har pårørende til kreftpasienter i ditt sykehus? Hva gjør de som er til hinder eller støtter opp om kvalitet og pasientsikkerhet? Nevn eksempler.
b) Melder pårørende inn avvik? Nevn eksempler. I så fall hvor meldes det og hvordan behandles disse? Formelt eller uformelt?
c) Hvordan betrakter helsepersonell pårørende som gir beskjed om kritikkverdige forhold? Hvem har ansvaret for å følge opp?
d) Hvor tilfreds tror du pårørende i ditt sykehus er med:
   - Den tid det tar før sykdommen blir påvist
   - Informasjon om forventet sykdomsutvikling
   - Den medbestemmelse familien har i behandlings- og pleiesituasjoner
   - Informasjon som blir gitt om hvordan en skal håndtere pasientens smerter
   - Tiden det tar før plager blir behandlet
   - Hvor lydhør helsepersonell er overfor pasientens beskrivelse av plager
   - Måten undersøkelser og behandling blir gjennomført
   - Legenes og sykepleiernes tilgjengelighet for familien

Pårørendes involvering

a) Blir pårørende involvert på en systematisk måte ved ditt sykehus med tanke på kvalitet og sikkerhet? (familiesamtaler, dokumenter etc)
b) Hvordan tenker du at pårørende til kreftpasienter kan/bør involveres mer systematisk? Kom med eksempler på hvordan og om du tror det er praktisk og realistisk gjennomførbart.
c) Er pårørendeinvolvering en ressurs for å skape trygghet, sikkerhet og effektive helsetjenester? I så fall på hvilken måte? Kan ditt sykehus/ avdeling involvere pårørende på en annen måte enn i dag? Kom gjerne med eksempler.

Støtte og utdanning av helsepersonell

a) Hvordan viser sykehuset/ledelsen at de verdsetter, belønner og respekterer kvalitet og sikkerhet?
b) Hvordan tilrettelegger ledelsen for at ansatte skal få holde seg faglig oppdatert?
c) Hvordan tilrettelegges det for at ansatte skal lære å ta i bruk pasient- og pårørende erfaringer i kreftomsorg og forbedring av kvalitet og sikkerhet?
d) Hvilken utdanning, kurs eller utviklingsprogrammer er tilgjengelig?

e) Samarbeider helsepersonell (leger, sykepleiere, hjelpepleiere) og ledere på en god måte for å forbedre kvalitet og pasientsikkerhet. Kan du gi eksempler.

Kvalitetsinformasjon, kultur og måling

a) Samles det inn spesifikke data fra pasienter og pårørende generelt eller knyttet til deres erfaringer?
b) Hvordan måler dere og rapporterer kvalitet og pasientsikkerhet ved denne avdelingen/sykehuset?
c) Hvilken informasjon om kvalitet og pasientsikkerhet kan helsepersonell på alle nivå få tilgang på? Kan pasienter og pårørende få tilgang på disse?
d) Hvordan brukes kvalitetsregistre og nasjonale kvalitetsindikatorer i din avdeling eller på sykehuset generelt?
e) Hvordan jobber man i denne avdelingen/enheten med å bygge en kultur som anerkjenner pasient og pårørendeinvolvering som en ressurs for helsetjenesten?

Deling av beste praksis

a) Hvordan blir god praksis delt på tvers av profesjon- og kliniske grenser på dette sykehuset? Nevn eksempler.
b) Finnes det nettverk eller møteplass for pårørende til kreftpasienter?
c) Hvor mye informasjon om kvalitet – og sikkerhet innen kreft feltet blir delt mellom sykehus i Norge og innad i helseregionen? Hvordan deles informasjonen? Formelle eller uformelle prosesser?

Ressurser

a) Hvilken praktisk støtte og kompetanse tilbyr dere helsepersonell i forbedringsarbeid? Hvordan følges det opp?
b) Settes det av tid og penger til forbedringsarbeid?
c) Hva annet tenker du at dere må gjøre for å lære opp og videreutvikle ansatte for å utviklekompetanse for involvering av pårørende?
d) Hvordan tenker du at pårørendeerfaringer eventuelt kan inkluderes i en slik opplæring?

Samhandling og ekstern kontekst

a) Finnes det nøkkelpersoner utenfor enheten eller utenfor sykehuset som du samarbeider med og som har et ekstra fokus på pårørende?
b) Er du eller din enhet en del av et bredere kvalitetsnettverk eller i samarbeid med andre organisasjoner?
c) Hvordan opplever du samarbeidet med kommunene når pasienten skal inn eller ut av din avdeling? Har pårørende en rolle i overgangene? Hvis ja, hvordan er pårørende en ressurs eller til hinder?
d) Hvordan dokumenteres samarbeidet med kommune og pårørende?

Eksternt miljø, større nettverk

a) Hvilke nasjonale strategier opplever du støtter/hindrer sykehusets kvalitet- og sikkerhetsarbeid? Hvilke andre har innvirkning på de ulike prioriteringene av tiltak i sykehuset?
b) Brukes guider/veiledere relatert til kvalitet- og sikkerhet på sykehus? Finnes det guider dere bruker innenfor kreft feltet?

Tusen takk for at du ville delta i forskningsprosjektet. Jeg slår av båndopptakeren nå.

Appendix 6

Interview guide healthcare professionals

Intervjuguide
Studie 1:Ansatte

Improving the quality and safety in hospital cancer care: A study of next-of-kin involvement

Finansiert av Stavanger Universitetssykehus

Takk for at du tok deg tid til å delta i dette forskningsprosjektet. Målsetningen med denne studien er å finne ny kunnskap om pårørendes rolle, betydning og involvering i kvalitet og pasientsikkerhetsforbedring i kreftomsorgen på to norske sykehus. Resultatene vil være med på å gi helsetjenesten ny kunnskap om hvordan pårørende kan inkluderes i det systematiske arbeidet for å forbedre kvalitet og pasientsikkerhet i kreftomsorgen på norske sykehus. Prosjektet skal resultere i en sjekkliste eller veileder for involvering av pårørende i kvalitet og pasientsikkerhetsforbedring.

Hensikten med dette intervjuet, og andre intervjuer vi gjør med ledere og helsepersonell på to sykehus er å undersøke hvordan organisasjonen jobber med kvalitet og pasientsikkerhetsforbedring og hvordan ledere og helsepersonell ser på pårørendes rolle i dette arbeidet. Hensikten er også å undersøke om intensjoner og praksis samsvarer, finne de beste metodene for involvering av pårørende i kvalitets- og pasientsikkerhetsforbedring og lære av gode strategier på tvers av sykehus innad i en helseregion.

Svarene dine blir ikke delt med noen utenfor forskningstemaet eller med andre av sykehusets ansatte. Intervjuene vil bli tatt opp på bånd og anonymiseres. Denne og andre samtaler blir transkribert og analysert av et forskerteam fra Universitetet i Stavanger og Stavanger Universitetssykehus. Alle data blir lagret på godkjent måte. Studien er godkjent av Regional etisk komité (prosjektnummer…) og av [personvernombud, sykehus].
(Pause til spørsmål og kommentarer. Kontroller at samtykkeskjemaet er lest, forstått og underskrevet. Hvis intervjuobjekt ønsker å gå videre settes opptakeren på.)

Innledningsspørsmål

a) Hvor lenge har du jobbet i denne enheten?
b) Hva er din rolle her?
c) Hva anser du som ditt ansvar og din rolle i forhold til kvalitet- og pasientsikkerhetsforbedring? (rolle knyttet til kliniske effektivitet, trygghet og sikkerhet i behandling og pleie, og pasient- og pårørende erfaringer)

Hvordan er det å jobbe i denne enheten

a) Hvordan er det å jobbe her sammenlignet med andre steder du har jobbet?
b) Hva er det du setter mest pris på med denne enheten og personalet?
c) Hva er utfordringene eller barrierene med jobben her?
d) Hva er det minst tilfredsstillende aspektet med å jobbe her?
e) Opplever du at dette er en god arbeidsplass med tanke på kvalitet og pasientsikkerhet?
f) Har du noen gang oppfordret pårørende eller pasienter til å si fra om kritikkverdige forhold du mener har gått ut over kvalitet og pasientsikkerhet?

Relasjon og samarbeid

a) På hvilken måte støtter og respekterer dere hverandre som kolleger i denne avdelingen?
b) Hvordan fungere det tverrfaglige samarbeidet? Hva støtter og hindrer arbeidet med kvalitet og sikkerhet?
c) Hvordan blir pasient og pårørende involvert i pleie og behandling?
d) Hvordan kan pårørende være en ressurs eller til hinder for god kvalitet og pasientsikkerhet? Nevn eksempler
e) Hvordan blir pårørende inkludert i pleie og behandling systematisk? I så fall på hvilken måte? Hvis ikke, bør de det?
f) Har du evn forslag til hvordan pårørende kan involveres mer systematisk, evn hvorfor bør ikke pårørende involveres?

Kultur, motivasjon og ledelse

a) Hvordan opplever du at det er en kultur for å involvere pårørende?
b) Snakker du og dine kolleger om feil eller uønskede hendelser?
c) Hvordan blir de ansattes bekymring om kvalitet og pasientsikkerhet hørt av ledelsen?
d) På hvilken måte bidrar ledelsen til kvalitetsforbedring og pasientsikkerhet? Nevn to eller tre ting som den overordnede organisasjonen gjør for å bedre kvalitet og sikkerhet som hjelper deg i den arbeidshverdag. Er det noe som hindrer deg?
e) Snakker ledelsen om pårørende og involvering av disse for å forbedre tjenesten?
f) Brukes det noen guider eller veiledere for kvalitet, pasientsikkerhet, kreft eller pårørende i dag? Nevn eksempler

Kvalitet og pasientsikkerhetsforbedring

a) Hvordan vil du vurdere sykehuset når det gjelder kvalitet og pasientsikkerhet sammenlignet med andre sykehus?
b) Bruker ansatte spesielle verktøy eller metoder for å forberede kvalitet og sikkerhet? Finnes det verktøy eller metoder for pårørende involvering på din avdeling?
c) Kan du peke på konkrete områder for forbedring av kvalitet og sikkerhet i din avdeling? Bruk eksempler
d) Bruker denne avdelingen konkrete tilbakemeldinger fra ansatte, pasienter eller pårørende til kvalitetsforbedring? I så fall hvor blir dette tatt opp?
e) Brukes læringsnotater fra kunnskapssentret eller tilbakemeldinger fra avvikssystemet til forbedring av kvalitet og sikkerhet ved din avdeling?
f) Settes det av tid og penger til forbedringsarbeid?

Opplæring i kvalitet og sikkerhet

a) Hvilke krav stiller arbeidsgiver til deg med tanke på kvalitet og pasientsikkerhet? (Utdanning, opplæring, annet)
b) Er det noen opplæring du føler du skulle hatt mer av eller savner?
c) Tilbyr avdelingen noen form for opplæring i hvordan kommunikasjon, informasjon og samarbeid med pasient, pårørende eller familie? (kurs eller lignende)
d) Kan pårørende være en kilde til kunnskap og læring? På hvilken måte og hvordan kan det gjennomføres?

Pårørendes rolle i kreftbehandlingen

a) Hvilken rolle har pårørende til kreftpasienter i din avdeling? (Er det noen karakteristika ved pårørende til kreftpasienter? Hva gjør de som er til hinder eller støtter opp om kvalitet og pasientsikkerhet? Nevn eksempler).

b) Hvordan har pårørende betydning for kvalitet og pasientsikkerhet? Begrunn svaret og kom med konkrete eksempler fra praksis
c) Hvordan samles erfaringene inn? Hvordan anvendes pårørende erfaringer?
d) Melder pårørende inn avvik? Nevn eksempler. I så fall hvor meldes det og hvordan behandles disse? Formelt eller uformelt?
e) Hvordan betrakter helsepersonell pårørende som gir beskjed om kritikkverdige forhold? Hvem har ansvaret for å følge opp?
f) Hva tror du er de tre viktigste kvalitetskriteriene pårørende har til kreftomsorgen i dag?

g) Hvor tilfreds tror du pårørende i din avdeling er med:
   - Den tid det tar før sykdommen blir påvist
   - Informasjon om forventet sykdomsutvikling
   - Den medbestemmelse familien har i behandlings- og pleiesituasjoner
   - Informasjon som blir gitt om hvordan en skal håndtere pasientens smerter
   - Tiden det tar før plager blir behandlet
   - Hvor lydhør helsepersonell er overfor pasientens beskrivelse av plager
   - Måten undersøkelser og behandling blir gjennomført
   - Legenes og sykepleiernes tilgjengelighet for familien

Informasjon, teknologi og støtte

a) Hvordan støtter eller hindrer IT systemer arbeidet med kvalitet og sikkerhet i din avdeling? (Cytodose, Dips, Synergi, annet…)
b) Hvordan fungere utstyret dere har i avdelingen (pumper eller andre overvåkningsutstyr)? Har dere nok tilgjengelige ressurser i avdelingen når det gjelder teknologisk utstyr som kreves ved avansert kreftbehandling?
c) Hvordan bidrar seksjonen som har ansvaret for kvalitet og pasientsikkerhet med ressurser, kompetanse, og involvering i praktisk forbedringsarbeid?
d) Er det andre nøkkelpersoner eller seksjoner du vil trekke frem som bidrar med ressurser, kompetanse og involvering i dette arbeidet?

Samhandling og ekstern kontekst

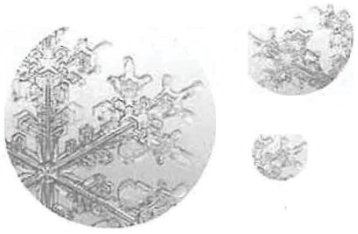
a) Finnes det nøkkelpersoner utenfor enheten eller utenfor sykehuset som du samarbeide med og som har et ekstra fokus på pårørende?
b) Er du eller din enhet en del av et bredere kvalitetsnettverk eller i samarbeid med andre organisasjoner?
c) Hvordan opplever du samarbeidet med kommunene når pasienten skal inne eller ut av din avdeling? Har pårørende en rolle i overgangene? Hvis ja, hvordan er pårørende en ressurs eller til hinder for kvalitet og pasientsikkerhet?
d) Hvordan dokumenteres samarbeidet med kommune og pårørende?

Er det noe du føler vi har glemt eller har lyst til å legge til. Tusen takk for at du ville delta forskningsprosjektet. Jeg slår av båndopptakeren nå.

Appendix 7

Approval FAMCARE scale

PRC European Palliative Care Research Centre
www.ntnu.no/prc



Trondheim, 13. mai 2015

Tillatelse til bruk av norsk oversettelse av «The 20-item FAMCARE scale survey instrument»

Inger Johanne Bergerød gis med dette tillatelse til bruk av norsk oversettelse av spørreskjemaet FAMCARE (1) sitt ph.d-prosjekt. Instrumentet er oversatt fra engelsk av forskere ved St. Olavs Hospital og NTNU og er i bruk i studier ved PRC. Oversettelsen er som avtalt sendt på mail til Bergerød.

Vennlig hilsen

Anne Kari Knudsen
MD, PhD, daglig leder / Administrative manager

Regional Centre for Palliative Care, Mid-Norway
European Palliative Care Research Centre, PRC

St. Olavs University Hospital | Faculty of Medicine, NTNU
Kunnskapssenteret 4.etg. øst, N-7006 Trondheim, Norway
Phone work + 47 72 82 62 96 | Cellphone +47 92 28 03 64
www.palliasjon-midt.no | www.ntnu.no/prc

1. Ringdal GI, Jordhoy MS, Kaasa S. Measuring quality of palliative care: psychometric properties of the FAMCARE Scale. Qual Life Res. 2003;12(2):167-76.

Appendix 8

Information for recruitment personnel

Versjon 28.09.16

INFORMASJONSSKRIV TIL DEG SOM SKAL INKLUDERE PÅRØRENDE TIL KREFTPASIENTER I EN SPØRRESKJEMAUNDERSØKELSE

Forskningsprosjekt:

Pårørendes rolle og betydning i arbeidet med kvalitet og pasientsikkerhet i kreftomsorgen på norske sykehus

Dette informasjonsskrivet inneholder viktige opplysninger for deg som skal inkludere pårørende til spørreskjemaundersøkelse i studie to av dette forskningsprosjektet.

Hva går forskningen ut på?
Hensikten med forskningsprosjektet er å utforske betydning av pårørendeinvolvering i kvalitets- og sikkerhetsarbeid innen kreftomsorgen. Resultatene vil være med på å gi helsetjenesten ny kunnskap om hvordan pårørende kan inkluderes i det systematiske arbeidet for å forbedre kvalitet og pasientsikkerhet i kreftomsorgen på norske sykehus.

Hvilke pårørende kan forespørres (inklusjonskriterier):
- Pårørende til alle typer kreftpasienter (alle diagnosegrupper kan inkluderes)
- Må ha hatt minimum kontakt med sykehuset, avdelingen eller poliklinikken i 3 måneder
- Pårørende over 18 år
- Samtykkekompetent
- Rekruttert via pasienten

Hvem skal ikke være med i studien (eksklusjonskriterier):
- Pårørende som er åpenbart kognitivt svekket (orienteringsevne/nedsatt bevissthetsnivå)
- Rusmisbrukere
- Ikke i stand til å lese/skrive norsk
- Pårørende under 18 år
- Inkludert tidligere i samme studie

Gjennomføring av inklusjonen:
- Avdelingssykepleier, prosjektleder eller studiesykepleier veileder sykepleierne på post/poliklinikk.
- Pasienten forespørres om inklusjon ved å vise informasjonsskriv om studiet, og eventuelt spørreskjema

Praktisk gjennomføring når pasient og pårørende har sagt ja til å være med:
- Dersom pasienten samtykker får pårørende spørsmål om de ønsker å være med enten via pasienten eller sykepleier.
- Fortrinnsvis er det mest praktisk hvis den pårørende kan svare når den er i avdelingen eller poliklinikken.
  Skjemaene kan også eventuelt sendes enten med pasienten eller via posten til den aktuelle pårørende (husk å sende med ferdigfrankert konvolutt med returadresse).

Etter utfylling:
Spørreskjema oppbevares i låsbart skap/kontor på den aktuelle enheten inntil de hentes av lokal koordinator eller prosjektansvarlig.

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Registrering og lagring av data og personopplysninger:
Utfylling av skjemaet regnes som samtykke i denne studien, derfor samles det ikke inn personopplysninger.

Kontakt for mer informasjon
Hvis du har spørsmål vedrørende denne studien, kan du kontakte doktorgradsstipendiat og prosjektleder Inger Johanne Bergerød via telefon 97753404 eller e-postadresse inger.johanne.bergerod@sus.no

Takk for at du tok deg tid til å lese denne informasjonen

Vennlig hilsen
Inger Johanne Bergerød
Phd stipendiat/ prosjektleder
Kreftsykepleier

Denne studien er godkjent av Regional etisk komité (prosjektnummer 2015/1488) og av Stavanger Universitetssykehus.

Appendix 9

Information for patient and next of kin

Versjon 28.09.16

INFORMASJONSSKRIV TIL DEG SOM ER PÅRØRENDE TIL EN KREFTPASIENT

Forskningsprosjekt:

Pårørendes rolle og betydning i arbeidet med kvalitet og pasientsikkerhet i kreftomsorgen på norske sykehus

Vi ønsker å spørre deg om du vil delta i dette forskningsprosjektet. Denne studien utføres av forskere fra Institutt for helsefag ved Universitetet i Stavanger og Stavanger universitetssykehus. I informasjonsskrivet redegjør vi for hvorfor forskningen utføres og hva den innebærer for deg, som mulig deltaker i studien. Vi ønsker at du tar deg tid til å lese informasjonen. Dersom noe er uklart vil du finne kontaktinformasjon på slutten av skrivet.

Hva går forskningen ut på?
Hensikten med forskningsprosjektet er å utforske betydning av pårørendeinvolvering i kvalitets- og sikkerhetsarbeid innen kreftomsorgen. Resultatene vil være med på å gi helsetjenesten ny kunnskap om hvordan pårørende kan inkluderes i det systematiske arbeidet for å forbedre kvalitet og pasientsikkerhet i kreftomsorgen på norske sykehus.

Hvorfor blir jeg spurt om å delta?
Stavanger Universitetssykehus har sagt ja til å delta i forskningsprosjektet og derfor får pårørende til kreftpasienter over 18 år tilbud om å bidra i forskningsprosjektet. Spørreskjemaundersøkelsen som du nå får tilbud om å være med på har til hensikt å finne ny kunnskap om hvordan pårørende kan inkluderes mer systematisk i kvalitet- og pasientsikkerhetsforbedring. Dette gjøres blant annet gjennom å måle pårørendes grad av tilfredshet med utvalgte områder som har betydning for kvalitet og pasientsikkerhet innen kreftomsorgen.

Får jeg noen fordeler med å delta?
Du får ingen direkte personlige fordeler ved å delta. Det kan imidlertid bli fordeler for sykehuset og helsetjenesten, fordi denne studien vil kunne legge grunnlaget for fremtidige kvalitetsstrategier og forbedring av pasientsikkerhet innen kreftomsorgen. Forskningsprosjektet skal resultere i en kunnskaps- og konsensusbasert sjekkliste/veileder for involvering av pårørende i kvalitet og pasientsikkerhetsforbedring. Sjekklisten/veilederen kan brukes av sykehusledere og ansatte for å skape en trygg, målrettet og systematisk organisering av helsetjenesten ved å involvere og ta i bruk pårørende erfaringer som en ressurs i forbedring av kvalitet og sikkerhet i kreftomsorgen.

Må jeg være med?
Det er opp til deg om du ønsker å være med eller ikke. Dersom du takker nei vil ikke dette ha innvirkning på nåværende eller fremtidig behandling og pleie av pasienten som du er pårørende til. Som deltaker vil alle dine opplysninger bli behandlet konfidensielt. Det blir ikke lagret navneliste som kobles til ditt spørreskjema.

Kontakt for mer informasjon
Hvis du har spørsmål vedrørende denne studien, kan du kontakte doktorgradsstipendiat og prosjektleder Inger Johanne Bergerød via telefon 97753404 eller e-postadresse inger.johanne.bergerod@sus.no

Takk for at du tok deg tid til å lese denne informasjonen

Inger Johanne Bergerød
Phd stipendiat/ prosjektleder
Kreftsykepleier

Denne studien er tilrådd av Regional etisk komité (prosjektnummer 2015/1488) og av personvernombudet på Stavanger Universitetssykehus.

Appendix 10

The survey

HELSE STAVANGER
Stavanger universitetssjukehus

Spørreskjema til pårørende [sykehus, enhet]

Vi ønsker å vite litt om deg og den du er pårørende til. Det er til stor hjelp hvis du tilstreber å svare på alle spørsmål.

Kort om deg som pårørende			
Din alder			
Kjønn	Mann	Kvinne	
Din relasjon til pasienten (ektefelle, barn, søsken)			
Antall hjemmeboende barn hos deg			
Høyeste fullførte utdanning for deg	Grunnskole	Videregående	Høyskole/Universitet
Hvor mye jobber du?	Full tid	Deltid	Ikke i arbeid
Kort om den du er pårørende til			
Pasientens kjønn	Mann	Kvinne	
Pasientens alder			
Pasientens diagnose			Vet ikke
Hvor mange måneder eller år har pasienten hatt kontakt med kreftavdelingen			

Spørsmålene under gjelder din vurdering av helsetilbudet som den du er pårørende til har fått. Tenk på de siste månedene og svar på spørsmålene ved å sette ett kryss i ruten for det svaralternativet som beskriver hvor tilfreds du var.

	Hvor tilfreds var du med:	Svært tilfreds (1)	Tilfreds (2)	Både og (3)	Lite tilfreds (4)	Svært lite tilfreds (5)	Ikke aktuelt
1.	Pasientens smertebehandling	1	2	3	4	5	
2.	Informasjon som ble gitt om forventet sykdomsutvikling	1	2	3	4	5	
3.	Svarene du fikk fra helsepersonell	1	2	3	4	5	
4.	Informasjon om bivirkninger av medisiner	1	2	3	4	5	
5.	Henvisninger til spesialist	1	2	3	4	5	
6.	Mulighetene for innleggelse i sykehus	1	2	3	4	5	
7.	Familiesamtaler holdt for å drøfte pasientens situasjon	1	2	3	4	5	
8.	Tiden det tok før plager ble behandlet	1	2	3	4	5	
9.	Hvor lydhøre helsepersonell er overfor pasientens beskrivelse av sine plager	1	2	3	4	5	
10.	Måten undersøkelser og behandling ble gjennomført på	1	2	3	4	5	
11.	Legenes tilgjengelighet for familien	1	2	3	4	5	
12.	Sykepleiernes tilgjengelighet for familien	1	2	3	4	5	
13.	Organisering av pasientens behandling og pleie	1	2	3	4	5	

	Hvor tilfreds var du med:	Svært tilfreds (1)	Tilfreds (2)	Både og (3)	Lite tilfreds (4)	Svært lite tilfreds (5)	Ikke aktuelt
14.	Den tiden det tok før sykdommen ble påvist	1	2	3	4	5	
15.	Den medbestemmelse familien hadde i behandlings og pleiesituasjonen	1	2	3	4	5	
16.	Informasjon om hvordan en skulle håndtere pasientens smerte	1	2	3	4	5	
17.	Informasjon som ble gitt om pasientens undersøkelser	1	2	3	4	5	
18.	Hvor godt legene vurderte pasientens plager	1	2	3	4	5	
19.	Måten legene fulgte opp undersøkelser og behandling på	1	2	3	4	5	
20.	Legenes tilgjengelighet for pasienten	1	2	3	4	5	

I tabellen under skal du velge ut TRE kriterier som er de viktigste for deg som pårørende når du tenker på kvalitet i kreftomsorgen. Ranger de tre kriteriene med tallene 1, 2 og 3 der 1 er mest viktig.

Kvalitetskriterier i kreftomsorgen	Velg ut kun **tre kvalitetskriterier**. Ranger de med tallene 1-3 der 1 er mest viktig	Begrunn kort hvis ønskelig
Helsepersonell med god utdanning		
Nærhet til sykehus og lege		
Behandling som virker		
Ingen ventelister		
Moderne medisinsk utstyr		
Respekt for pasientens verdighet		
Fritt valg av lege		
Fritt valg av sykehus		
Imøtekommende omgivelser		
Rene omgivelser i lokaler		
Sikring mot skade		
Annet, spesifiser:		

Basert på dine erfaringer – hvordan bør involvering av pårørende gjøres for å bedre kvalitet og pasientsikkerhet innen kreftomsorgen? Har du forslag til konkrete tiltak?

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Takk for at du tok deg tid til å svare på denne undersøkelsen!