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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.

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
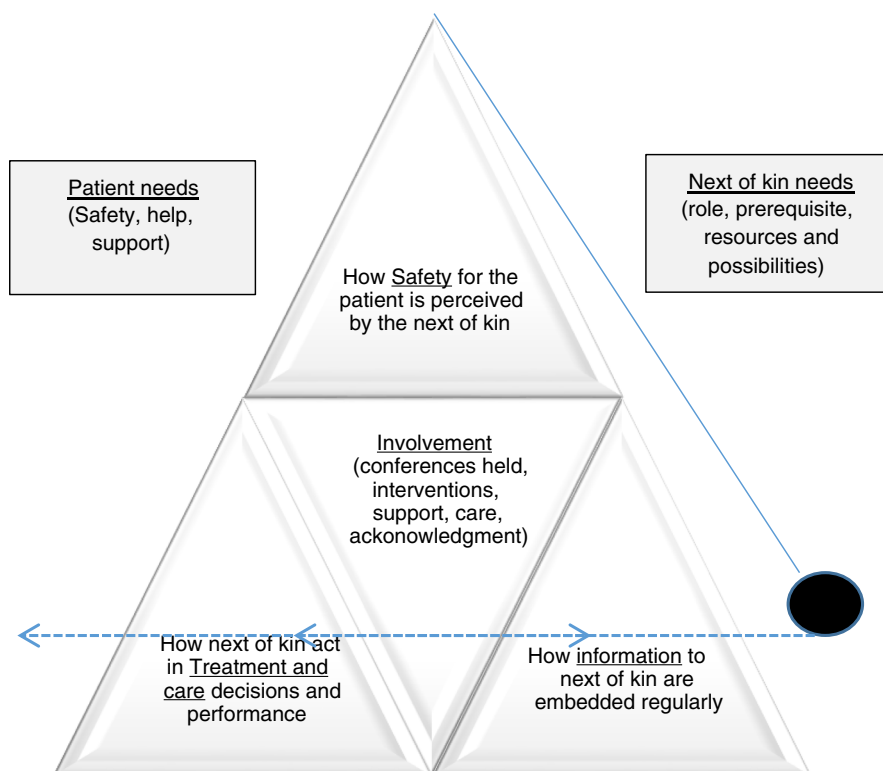

FIGURE 1 The involvement pendulum [Colour figure can be viewed at wileyonlinelibrary.com]

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	% 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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REFERENCES
Aase, K., Laugaland, K. A., Dyrstad, D. N., & Storm, M. (2013). Quality and safety in transitional care of the elderly: The study protocol of a case study research design (phase 1). *British Medical Journal Open*, 3(8), e003506. https://doi.org/10.1136/bmjopen-2013-003506

Aspinal, F., Addington-Hall, J., Hughes, R., & Higginson, I. J. (2003). Using satisfaction to measure the quality of palliative care: A review of the literature. *Journal of Advanced Nursing*, 42(4), 324–339. https://doi.org/10.1046/j.1365-2648.2003.02624.x

Augustussen, M., Hounsgaard, L., Pedersen, M. L., Sjogren, P., & Timm, H. (2017). Relatives' level of satisfaction with advanced cancer care in Greenland - a mixed methods study. *International Journal of Circumpolar Health*, 76(1), 1335148. https://doi.org/10.1080/22423982.2017.1335148

Barrera-Gómez, J., & Basagaña, X. (2015). *Models with Transformed Variables Interpretation and Software*, 26(2), e16–e17. https://doi.org/10.1097/EDE.0000000000000247

Bate, P., Mendel, P., & Robert, G. (2008). *Organizing for Quality : The Improvement Journeys of Leading Hospitals in Europe and The United States*. Oxford: Radcliffe.

Beaumont, C. & Nekolaichuk, C. (2019). FAMCARE and FAMCARE-2 Guidelines. Version 2.0: 08. December, 2012.

Bergerød, I. J., Braut, G. S., & Wiig, S. (2018). Resilience from a stakeholder perspective: The role of next of kin in cancer care. *Journal of Patient Safety*. Epub ahead of Print. https://doi.org/10.1097/pts.0000000000000532

Bergerød, I. J., Gilje, B., Braut, G. S., & Wiig, S. (2018b). Next-of-kin involvement in improving hospital cancer care quality and safety – a qualitative cross-case study as basis for theory development. *BMC Health Services Research*, 18(1), 324. https://doi.org/10.1186/s12913-018-3141-7

Blindheim, K., Thorsnes, S. L., Brataas, H. V., & Dahl, B. M. (2013). The role of next of kin of patients with cancer: Learning to navigate unpredictable caregiving situations. *Journal of Clinical Nursing*, 22(5–6), 681–689. https://doi.org/10.1111/j.1365-2702.2012.04349.x

Can, G., Akin, S., Aydiner, A., Ozdilli, K., Oskay, U., & Durna, Z. (2011). A psychometric validation study of the quality of life and FAMCARE scales in Turkish cancer family caregivers. *Quality of Life Research*, 20(8), 1319–1329. https://doi.org/10.1007/s11136-011-9867-x

Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. SAGE Publications.

Creswell, J. W. (2015). *A concise introduction to mixed methods research*. Thousand Oaks, CA: SAGE.

Croskerry, P., Abbass, A., & Wu, A. W. (2010). Emotional influences in patient safety. *Journal of Patient Safety*, 6(4), 199–205. https://doi.org/10.1097/PTS.0b013e3181f6c01a

Davies, E., & Cleary, P. D. (2005). Hearing the patient's voice? Factors affecting the use of patient survey data in quality improvement. *Quality and Safety in Health Care*, 14(6), 428. https://doi.org/10.1136/qshc.2004.012955

Davis, P., Milne, B., Parker, K., Hider, P., Lay-Yee, R., Cumming, J., & Graham, P. (2013). Efficiency, effectiveness, equity (E3). Evaluating hospital performance in three dimensions. *Health Policy*, 112(1), 19–27. https://doi.org/10.1016/j.healthpol.2013.02.008

Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *British Medical Journal Open*, 3(1), e001570. https://doi.org/10.1136/bmjopen-2012-001570

Dy, S. M., Shugarman, L. R., Lorenz, K. A., Mularski, R. A., & Lynn, J. (2008). A Systematic Review of Satisfaction with Care at the End of Life. *Journal of the American Geriatrics Society*, 56(1), 124–129. https://doi.org/10.1111/j.1532-5415.2007.01507.x

Ekstedt, M., Stenberg, U., Olsson, M., & Ruland, C. M. (2014). Health care professionals' perspectives of the experiences of family caregivers during in-patient cancer care. *Journal of Family Nursing*, 20(4), 462–486. https://doi.org/10.1177/1074840714556179

Fetters, M. D., Curry, L. A., & Creswell, J. W. (2013). Achieving integration in mixed methods designs-principles and practices. *Health Services Research*, 48(6 Pt 2), 2134–2156. https://doi.org/10.1111/1475-6773.12117

Fisher, K. A., & Mazor, K. M. (2017). Patient and family complaints in cancer care: What can we learn from the tip of the iceberg? *The Joint Commission Journal on Quality and Patient Safety*, 43(10), 495–497. https://doi.org/10.1016/j.jcjq.2017.07.003

Given, B. A., Given, C. W., & Sherwood, P. R. (2012). Family and caregiver needs over the course of the cancer trajectory. *The Journal of Supportive Oncology*, 10(2), 57–64. https://doi.org/10.1016/j.suponc.2011.10.003

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001.

Groene, O., Sunol, R., Klazinga, N. S., Wang, A., Dersarkissian, M., Thompson, C. A., ... Thompson, A. (2014). Involvement of patients or their representatives in quality management functions in EU hospitals: Implementation and impact on patient-centred care strategies. *International Journal for Quality in Health Care*, 26(Suppl 1), 81–91. https://doi.org/10.1093/intqhc/mzu022

Hannon, B., Swami, N., Krzyzanowska, M. K., Leighl, N., Rodin, G., Le, L. W., & Zimmermann, C. (2013). Satisfaction with oncology care among patients with advanced cancer and their caregivers. *Quality of Life Research*, 22(9), 2341–2349. https://doi.org/10.1007/s11136-013-0371-3

Hollnagel, E. (2017). *Safety-II in Practice: Developing the Resilience Potentials*. London: Taylor & Francis.

Horn, J. L. (1965). A rationale and test for the number of factors in factor analysis. *Psychometrika*, 30, 179–185. https://doi.org/10.1007/BF02289447

Johnsen, A. T., Ross, L., Petersen, M. A., Lund, L., & Groenvold, M. (2012). The relatives' perspective on advanced cancer care in Denmark. A cross-sectional Survey. *Support Care Cancer*, 20(12), 3179–3188. https://doi.org/10.1007/s00520-012-1454-3

Kim, H., & Yi, M. (2015). Unmet needs and quality of life of family caregivers of cancer patients in South Korea. *Asia-Pacific Journal of Oncology Nursing*, 2(3), 152–159. https://doi.org/10.4103/2347-5625.158019

Kringos, D. S., Sunol, R., Wagner, C., Mannion, R., Michel, P., Klazinga, N. S., & Groene, O. (2015). The influence of context on the effectiveness of hospital quality improvement strategies: A review of systematic reviews. *BMC Health Services Research*, 15, 277. https://doi.org/10.1186/s12913-015-0906-0

Kristjanson, L. J. (1993). Validity and reliability testing of the FAMCARE Scale: Measuring family satisfaction with advanced cancer care. *Social Science and Medicine*, 36(5), 693–701. https://doi.org/10.1016/0277-9536(93)90066-D

Laidsaar-Powell, R., Butow, P., Bu, S., Charles, C., Gafni, A., Fisher, A., & Juraskova, I. (2016). Family involvement in cancer treatment decision-making: A qualitative study of patient, family and clinician attitudes and experiences. *Patient Education and Counseling*, 99(7), 1146–1155. https://doi.org/10.1016/j.pec.2016.01.014

Lawton, R., O'Hara, J. K., Sheard, L., Armitage, G., Cocks, K., Buckley, H., ... Wright, J. (2017). Can patient involvement improve patient safety? A cluster randomised control trial of the patient reporting and action for a safe environment (PRASE) intervention. *BMJ Quality & Safety*, 26(8), 622–631. https://doi.org/10.1136/bmjqs-2016-005570

Litzelman, K., Kent, E. E., Mollica, M., & Rowland, J. H. (2016). How does caregiver well-being relate to perceived quality of care in patients with cancer? Exploring associations and pathways. *Journal of Clinical Oncology*, 34(29), 3554–3561. https://doi.org/10.1200/JCO.2016.67.3434

McCarthy, B. (2011). Family members of patients with cancer: What they know, how they know and what they want to know. *European Journal of Oncology Nursing*, 15(5), 428–441. https://doi.org/10.1016/j.ejon.2010.10.009

Norwegian Ministry of Health and Care Services (2011). NOU 2011:17 Når sant skal sies om pårørendeomsorgen - fra usynlig til verdsatt og inkludert (In Norwegian).

Norwegian Ministry of Health and Care Services (2013–2017). *National cancer strategy. Together- against cancer. (I-1158 B)*. Oslo, Norway: Norwegian Ministry of Health and Care Services.

Norwegian Ministry of Health and Care Services (2015). Care Plan 2020 - The Norwegian Government's Plan for The Care Services Field for 2015–2020.

Nyborg, I., Danbolt, L. J., & Kirkevold, M. (2017). User participation is a family matter: A multiple case study of the experiences of older, hospitalised people and their relatives. *Journal of Clinical Nursing*, 26(23-24), 4353–4363. https://doi.org/10.1111/jocn.13765

O'Hara, J. K., Aase, K., & Waring, J. (2018). Scaffolding our systems? Patients and families 'reaching in' as a source of healthcare resilience. *BMJ Quality & Safety*, 28(1), 3–6. https://doi.org/10.1136/bmjqs-2018-008216

O'Cathain, A., Murphy, E., & Nicholl, J. (2010). Three techniques for integrating data in mixed methods studies. *BMJ*, 341, c4587. https://doi.org/10.1136/bmj.c4587

O'Hara, J. K., Canfield, C., & Aase, K. (2019). Patient and family perspectives in resilient healthcare studies: A question of morality or logic? *Safety Science*, 120, 99–106. https://doi.org/10.1016/j.ssci.2019.06.024

Östlund, U., Kidd, L., Wengström, Y., & Rowa-Dewar, N. (2011). Combining qualitative and quantitative research within mixed method research designs: A methodological review. *International Journal of Nursing Studies*, 48(3), 369–383. https://doi.org/10.1016/j.ijnurstu.2010.10.005

Partanen, E., Lemetti, T., & Haavisto, E. (2018). Participation of relatives in the care of cancer patients in hospital-A scoping review. *European Journal of Cancer Care*, 27(2), e12821. https://doi.org/10.1111/ecc.12821

Patton, M. (1990). *Qualitative evaluation and research methods* (pp. 169–186). Beverly Hills, CA: Sage.

Polit, D. F., & Beck, C. T. (2014). *Essentials of nursing research : Appraising evidence for nursing practice.* (8th ed.). Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins.

Revelle, W. (2018). *psych: Procedures for personality and psychological research*. Evanston, IL: Northwestern University. Version 1.8.4. https://CRAN.Rproject.org/package=psych

Ringdal, G. I., Jordhoy, M. S., & Kaasa, S. (2002). Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. _Journal of Pain and Symptom Management_, 24(1), 53–63. Retrieved from http://ac.els-cdn.com/S0885392402004177/1-s2.0-S0885392402004177-main.pdf?_txml:id=3db5b63a-514d-11e5-9f12-00000aacb35d&acdnat=1441182969_2e42411c27a0c74af798b76a326fece5.

Ringdal, G. I., Jordhoy, M. S., & Kaasa, S. (2003). Measuring quality of palliative care: Psychometric properties of the FAMCARE Scale. _Quality of Life Research_, 12(2), 167–176.

Rodriguez, K. L., Bayliss, N. K., Jaffe, E., Zickmund, S., & Sevick, M. A. (2010). Factor analysis and internal consistency evaluation of the FAMCARE scale for use in the long-term care setting. _Palliative and Supportive Care_, 8(2), 169–176. https://doi.org/10.1017/s1478951509990927

Romito, F., Goldzweig, G., Cormio, C., Hagedoorn, M., & Andersen, B. L. (2013). Informal caregiving for cancer patients. _Cancer_, 119(Suppl 11), 2160–2169. https://doi.org/10.1002/cncr.28057

Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. _Psychooncology_, 19(10), 1013–1025. https://doi.org/10.1002/pon.1670

Storm, M., Siemsen, I. M., Laugaland, K., Dyrstad, D. N., & Aase, K. (2014). Quality in transitional care of the elderly: Key challenges and relevant improvement measures. _International Journal of Integrated Care_, 14, e013. https://doi.org/10.5334/ijic.1194

Thorsnes, S. L., Blindheim, K., & Brataas, H. V. (2014). Next of kin of cancer patients - challenges in the situation and experiences from a next of kin course. _European Journal of Oncology Nursing_, 18(6), 578–584. https://doi.org/10.1016/j.ejon.2014.07.001

Tranberg, M., Andersson, M., Nilbert, M., & Rasmussen, B. H. (2019). Co-afflicted but invisible: A qualitative study of perceptions among informal caregivers in cancer care. _Journal of Health Psychology_, https://doi.org/10.1177/1359105319890407

Tritter, J. Q. (2009). Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. _Health Expectations_, 12(3), 275–287. https://doi.org/10.1111/j.1369-7625.2009.00564.x

Ugalde, A., Gaskin, C. J., Rankin, N. M., Schofield, P., Boltong, A., Aranda, S., … Livingston, P. M. (2019). A systematic review of cancer caregiver interventions: Appraising the potential for implementation of evidence into practice. _Psychooncology_, https://doi.org/10.1002/pon.5018

van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J. M., Martin, M., … Rowland, J. (2011). Objective burden, resources and other stressors among informal cancer caregivers: A hidden quality issue? _Psychooncology_, 20(1), 44–52. https://doi.org/10.1002/pon.1703

Vincent, C., & Davis, R. (2012). Patients and families as safety experts. _Canadian Medical Association Journal_, 184(1), 15–16. https://doi.org/10.1503/cmaj.111311

Wells, K. J., Campbell, K., Kumar, A., Clark, T., & Jean-Pierre, P. (2018). Effects of patient navigation on satisfaction with cancer care: A systematic review and meta-analysis. _Supportive Care in Cancer_, 26(5), 1369–1382. https://doi.org/10.1007/s00520-018-4108-2

Willis, R., Evandrou, M., Pathak, P., & Khambhaita, P. (2016). Problems with measuring satisfaction with social care. _Health and Social Care in the Community_, 24(5), 587–595. https://doi.org/10.1111/hsc.12231

SUPPORTING INFORMATION

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