

Patients' Perceptions Of The Quality Of Palliative Care And Satisfaction – A Cluster Analysis

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Purpose: Palliative care services are multidisciplinary, and the quality needs to be evaluated from the patients' perspectives. The aim was to explore the patient profiles in palliative care with respect to patients' perception of the quality of palliative care received and patient satisfaction, and to describe and compare person-related and organization-related conditions that characterize the patient profiles.

Patients and methods: A cross-sectional study, including 140 patients from four different multidisciplinary palliative care contexts in Norway, was conducted in 2014. The Quality from the Patient's Perspective questionnaire for Palliative Care, which is based upon a person-centered theoretical model, was used. Satisfaction was measured by the Emotional Stress Reaction questionnaire. Person- and organization-related conditions were measured. Hierarchical cluster analysis, ANOVA, Pearson Chi-Square Test and ANCOVA were used.

Results: Three unique patient clusters with different patterns of perceptions of quality of care and satisfaction were identified; Cluster 1 (41%) had the best perception of care quality and were more satisfied, Cluster 2 (34%) had better perceptions of care quality and were most satisfied and Cluster 3 (25%) had worst perceptions of care quality and were less satisfied. The clusters were characterized by person-related conditions (eg, patients' sense of coherence and perceptions of subjective importance of the quality) as well as organization-related conditions (eg, physicians' competence and type of care services).

Conclusion: The results can be used by multidisciplinary healthcare personnel to tailor quality work and improve person-centered care in palliative care contexts. Improvement initiatives should focus on implementing a person-centered approach, increasing the palliative care competence of the personnel and facilitate specialized palliative care services in the homecare context.

Keywords: emotional stress reaction questionnaire, ESRQ, patient satisfaction, quality of healthcare, quality from the patients' perspective specific for palliative care, QPP-PC

Introduction

The number of patients with life-threatening illnesses in developed countries will continue to increase because people get older and live longer with illnesses with complex needs.¹ Consequently, the need for high-quality multidisciplinary palliative care tailored to the individual patient will also increase. The quality of palliative care services needs to be evaluated.²⁻⁴ To gain knowledge of how patients with life-threatening illnesses in need of palliative care experience healthcare quality, it is important to ask the individuals in question. Patients with life-threatening illnesses and in need of palliative care include patients with cancer and patients with other illnesses^{5,6} like chronic obstructive pulmonary disease and heart failure. Patients' perceptions of their care may be seen as one aspect

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of quality of healthcare,^{5,7} and is considered important for evaluation, development and improvement of palliative care.^{4,5,7,8} Patients tend to evaluate the quality of healthcare positively when hospitalized. It might seem that most patients form a homogenous group that is reasonably pleased, and consequently the need for quality improvements is almost non-existent. However, studies that have used cluster analysis to explore similarities and differences among hospital patients' healthcare quality evaluations and satisfaction have revealed significantly different patient groups. One study found three groups where one group scored low on satisfaction, but high on perceptions of care quality.⁹ The clusters were significantly different with regard to person-related and organizational conditions. Another study using cluster analysis identified six significantly different groups including one group with systematically poorer evaluation on all outcomes.¹⁰ The patient groups were significantly associated with age, education, self-perceived health and gender. In a nursing home, one study, using the questionnaire quality from the patient's perspective, identified two significantly different clusters, one cluster with best care quality perceptions and one with the worst care quality perceptions. The clusters were significantly associated with both person-related conditions and the organizational conditions healthcare personnel and registered nurses (RNs).¹¹ No similar studies are available for quality of palliative care. In addition, previous studies also found that there is a need for quality improvement in palliative care.^{12,13}

In healthcare quality research, there is a confusion between patient perceptions and actual experiences of the healthcare received and patients' satisfaction.^{14–16} These terms are often used interchangeably within and between studies and it is unclear how perceptions of healthcare quality, experiences and satisfaction are measured.

Quality of healthcare comprises process, structure and outcome, and can be viewed from different perspectives depending on who defines the term: patients, relatives, healthcare personnel, administrators or politicians.¹⁷ Patient-reported outcome measure (PROM) and patient-reported experience measure (PREM) are classifications of healthcare quality evaluation from the patients' perspective. PROM comprises measures of outcomes of the healthcare delivered, like quality of life, while PREM comprises patients' experiences and perceptions of the quality of healthcare delivered.¹⁸

In this study, care quality is based on the theoretical model of Quality of Care from the Patients' Perspective¹⁹ which can be classified within PREM. The model states that quality of care concerns two conditions: the resource structure of the care organization, which includes person-related, physical and

administrative environmental qualities, and the patients' preferences, that include the human and rational aspects.¹⁹ Based on this model, the quality from the patients' perceptions questionnaire (QPP) was developed.²⁰ The QPP questionnaire measures care quality with items related to four quality dimensions: the medical–technical competence and the identity-oriented approach of the caregivers and the physical–technical conditions and the sociocultural atmosphere of the care organization.²⁰ Patients evaluate the care quality in two ways: how they perceive the reality of the quality of care received (PR) and the subjective importance of the various aspects of care (SI).

Satisfaction is among others described as an emotion, an attitude, an opinion of healthcare and of life in general.²¹ In this study, satisfaction is based on a theoretical framework with the following three assumptions: emotions in a given situation show how the situation is interpreted cognitively, the cognitive interpretation indicates the strength of the stress reaction in a given situation and the strength of the reaction to stress in a given situation predicts the person's potential for psychological coping in the situation.^{22,23}

Contradictions between high levels of satisfaction and poor experiences among patients are uncovered.^{9,24–26} In example, one study identified three cluster groups of patients, where one group scored low on satisfaction, but high on perceptions of care quality.⁹ Therefore, further studies that investigate the relationship between satisfaction as an emotion and perceptions of the quality of palliative care from the patients' perspective are needed. The relationship can be more deeply understood by using cluster analysis and by exploring the different clusters' characteristics with respect to person-related conditions and organization-related conditions. Cluster analysis may uncover patients' characteristics: those who consider palliative care quality better and those who consider it worse, and thus allow palliative care quality work to be more person-centered and tailored to where it is most needed for persons in need of palliative care.

The aim of the study presented here, therefore, was to explore the profiles of patients in palliative care with respect to patients' perception of the quality of palliative care received and patient satisfaction, and to describe and compare person-related conditions and organization-related conditions that characterize the patient profiles.

Methods

This study used data from a cross-sectional study conducted in Norway between November 2013 and December 2014.

The settings, participations and procedures have been described more comprehensively in a previous publication.¹³

Participants And Procedures

Participants were recruited from two inpatient hospices, two hospice day-care centers, two palliative units in nursing homes that specialized in palliative care and two homecare districts in Norway. Patients in all of the care settings had access to multidisciplinary healthcare personnel. In each ward, a registered nurse (RN) was responsible for recruiting participants (RRN). The following inclusion criteria were used: adult (≥ 18 years), understands Norwegian, has no cognitive impairment, received care from the services for at least 3 days and has an advanced, life-threatening illness in a late palliative phase (malignant or non-malignant). This was judged and guided by the RRN's negative response to the question: "Would you be surprised if this patient died within the next year?".²⁷ Patients included in the study should be aware of being in a palliative phase and receiving palliative care (judged by the RRN). The RRNs were encouraged to consult with patients' physicians and the first author to discuss any uncertainties about the inclusion criteria, and whether or not to include patients in the study. Patients were asked to participate and provided with verbal and written information about voluntary participation, information about the study and how to fill out the questionnaire by the RRN. The questionnaire was returned in a sealed envelope and stored in the RRNs' offices before collection by the researcher. Patients were offered help with filling out the questionnaire as an interview with the first author (TS). Of the 140 participants, 35 (26%) were interviewed. Patients were interviewed either in a private room in the ward or in the patients' homes. The interview was conducted such that each question in the questionnaire was read aloud to the respondent. The researcher then wrote the responses in the questionnaire after each question.

Data Collection

Data were collected from patients by a questionnaire comprising patients' perceptions of the care quality, perceptions of satisfaction of care and person-related conditions, as for example age, gender and education. Data were also collected from head nurse in the care context included regarding organization-related conditions.

Cluster Variables

The Quality from the Patient's Perspective questionnaire for Palliative Care (QPP-PC) was used to measure the care

quality. Satisfaction was measured by the Emotional Stress Reaction questionnaire (ESRQ).

Patients' perceptions of palliative care quality received were measured by the Quality from the Patient's Perspective questionnaire specific to Palliative Care (QPP-PC).²⁸ This is a person-centered instrument that comprises four dimensions with 12 factors (49 items) and three single items. The QPP-PC is based on the theoretical foundation (conceptual model) of the validated general instrument QPP,^{19,20} which comprises four dimensions representing quality of care: the medical-technical competence of the caregiver (MT), the physical-technical conditions of the care organization (PT), the identity-oriented approach of the caregivers (ID) and the sociocultural atmosphere of the care organization (SC). In addition, QPP-PC includes three single items: Medical care, Help to take care of personal hygiene and Atmosphere on the ward. From this, care quality can be seen as patients' perceptions of the actual care received (the perceived reality [PR-scale]) and perceptions of how important the various care aspects are to them (the subjective importance of the care aspects [SI-scale]).²⁰ The questionnaire comprises questions related to a multidisciplinary staff that is often present in palliative care (physicians, nurses and other personnel, which refers to assistant nurses, priests, physiotherapists, occupational therapists or social workers). The cluster variable used in this paper was the PR scale, including the four dimensions and the single item about medical care. The single items in QPP-PC about personal hygiene and atmosphere in the ward were excluded from the cluster analysis due to being systematically missing, since these items typically were scored "not applicable" by patients from hospice day care (personal hygiene) and patients living at home (atmosphere in the ward).

For each item of the PR scale, patients scored their opinions of the quality of actual care received (PR) related to the sentence "This is what I experience ..." (eg, personnel are respectful to me) on a 4-point Likert-type scale, ranging from 1 (do not agree at all) to 4 (fully agree). A non-applicable alternative was available for each response. A mean score was calculated for each dimension by adding the item scores and dividing the sum by the number of items within the respective dimension. Cronbach's alpha values for the dimension in the PR scale were above 0.7 for all dimensions (MT: 0.89, ID: 0.89, SC: 0.89), except for PT dimension which was 0.45.

Satisfaction was measured by the Emotional Stress Reaction Questionnaire (ESRQ)²³ which measures

satisfaction by an emotional-oriented approach. The instrument is based on a theoretical framework²² which was further developed and adapted to a care context version²³ and translated into Norwegian.²⁹ The instrument contains 30 emotion words which are scored by patients on a Likert-type scale ranging from 1 (the word does not correspond to how I feel right now) to 4 (the word completely corresponds to how I feel right now). Total score ranges from -58 (maximum dominance of negative emotions) to +23 (maximum dominance of positive emotions). The Cronbach's alpha value in this present sample of patients for the ESRQ scale was 0.78.

Descriptive Variables – Person-Related Conditions

Person-related conditions comprised:

Socio-demographic variables from the QPP-PC questionnaire comprised age, gender, education, type of diagnosis, time in care (five items).

Data on health-related quality of life were collected, using the EuroQol-visual analogue scale: EQ-VAS from the EQ-5D-3L questionnaire developed by the EuroQol Group (one item).^{30,31} This questionnaire is a standardized generic measure of health-related quality of life, designed for self-completion by respondents.^{32,33} The EQ-VAS is an overall measure of health-related quality of life which measures the respondent's self-rated health on a vertical, visual analogue scale ranging from 0 to 100. The end-points are labelled "best imaginable health state" (100) and "worst imaginable health state" (0). The score shows how patients perceive their health-related quality of life. A mean value was calculated to describe the health-related quality of life in the sample of patients.

Psychological well-being was measured by one item from the QPP questionnaire, related to the sentence: "I feel that my physiological well-being is ...", using a 5-point Likert-type scale ranging from 1 ("very poor") to 5 ("very good").²⁰ A mean value was calculated to describe the psychological well-being of the patients.

Patients' preferences of the subjective importance of the care aspects (SI) were measured by using the SI scale comprising the four dimensions and one single item about medical care of the QPP-PC. For each item of the SI scale, patients scored the subjective importance of care aspects (SI) related to the sentence "This is how important this is to me ..." (eg, personnel are respectful to me) on a Likert-type scale ranging from 1 (of little or no importance) to 4 (of the very highest importance). A non-applicable alternative was available for each response. A mean score was calculated for each dimension by adding the item scores and dividing the sum by the number

of items within the respective dimension. Cronbach's alpha values for the dimension in the SI scale were above 0.7 for all dimensions (MT: 0.91, ID: 0.94, SC: 0.92), except for the PT dimension which was 0.65.

The sense of coherence (SOC) scale (13 items) is developed to measure a patient's life orientation,^{34–36} and is an operationalization of the construct: the sense of coherence, in the theoretical salutogenic model developed to explain how people manage stressful situations and stay well. The scale comprises questions about comprehensibility, manageability and meaningfulness. Each item, eg, "Do you have the feeling that you're being treated unfairly?", is scored on a 7-point response scale ranging from 1 ("very often") to 7 ("very seldom or never"). The SOC index was calculated by adding the score from each item, ranging from 13 to 91. High scores represent a strong SOC. The Cronbach's alpha value for the SOC scale in this present sample of patients was 0.78.

Descriptive Variables – Organization-Related Conditions

Organization-related conditions comprised: organizational model for nursing care, physicians' competence in palliative care and type of care services.

Organizational model for nursing care was measured by the question "The organization model for nursing care was ..." with the response alternatives: team nursing/primary nursing/other. This variable was dichotomized into: Team nursing and primary nursing.

Physicians' competence in palliative care was measured by a question about whether the physicians in the care services had achieved specialized education in palliative care medicine (yes/no).

Type of care services was the services the participants were recruited from: inpatient hospices, hospice day-care centers, palliative units in nursing homes that specialized in palliative care and homecare districts.

Statistical Analysis

IBM SPSS version 25 was used to analyze the data. The descriptive statistics: mean, standard deviation, frequency and percent were used to characterize the study sample and the patients' care quality perceptions and satisfaction. Hierarchical cluster analysis on Z-standardization, using Ward's method with squared Euclidean distance as the similarity measure, was conducted to identify patterns of clusters with high homogeneity within the clusters and high heterogeneity between the clusters related to the cluster variable perceptions of care quality and satisfaction with palliative

care.^{37,38} To compare the clusters, ANOVA with Tukey post hoc tests were used. To describe cluster characteristics according to person- and organization-related conditions, ANCOVA was run on continuous variables and Pearson Chi-Square Test was used on categorical variables. Statistical significance was $p < 0.05$.

Results

Description Of The Participants

A total of 191 patients (RR 73%) agreed to participate. Of these, 140 patients who gave complete answers for the cluster variables were included in this study. Patients had a mean age of 65 (range: 41–94) years, 54% were women, 62% had compulsory/high school education or equivalent, and 38% had university/university college level of education, 83% had cancer and 17% had non-malignant illnesses, and 36% were admitted to inpatient hospices, 30% to hospice day-care centers, 17% in palliative units in nursing homes and 17% in homecare districts.

Cluster Description

The analysis identified three unique clusters of patients with different patterns of perceptions of quality of care received (perceived reality scale) and satisfaction. Table 1 shows the characteristics of patients' perceptions of quality of care and satisfaction for each unique cluster of patients. The wording of the clusters indicates the relationship between the clusters.

The clusters were characterized by statistically significant differences in the following person-related conditions: patients' sense of coherence (SOC) and the patients' perceptions of the subjective importance (subjective importance scale) related to the care aspects at the level of dimensions and single items (Table 2). Age, gender, education, type of illness and health-related quality of life did not differ significantly between the clusters.

The clusters were also characterized by statistically significant differences in the following organization-related conditions: physicians' competence in palliative care (palliative medicine as a subspecialty), and type of care services (Table 3). Organizationally related conditions on the organizational model for nursing care did not differ statistically significant between the clusters.

Cluster 1: Best Perception Of Care Quality – More Satisfied

Patients in Cluster 1 represented 41% of the respondents and had “best perception of care quality and were more satisfied”. Patients in this cluster scored statistically significantly higher on all care quality dimensions on the perceived reality scale and single items than patients in Clusters 2 and 3. Satisfaction was scored statistically significantly higher for patients in Cluster 1 than patients in Cluster 3.

When comparing the patients in the three clusters regarding person-related conditions, patients' perceptions of subjective importance (subjective importance scale) for the following quality dimensions and single items were scored statistically

Table 1 Cluster Description

Cluster	1	2	3	
Description	Best Perception Of Care Quality And More Satisfied	Better Perceptions Of Care Quality And Most Satisfied	Worst Perceptions Of Care Quality And Less Satisfied	
n (%)	57 (41)	48 (34)	35 (25)	P*
	Mean (SD)	Mean (SD)	Mean (SD)	
Medical–technical competence (PR)	3.65 (0.35)	2.74 (0.54)	2.61 (0.66)	<0.001
Physical–technical conditions (PR)	3.82 (0.33)	3.59 (0.33)	2.78 (0.63)	<0.001
Identity-oriented approach (PR)	3.68 (0.32)	3.34 (0.43)	2.87 (0.40)	<0.001
Socio-cultural atmosphere (PR)	3.67 (0.33)	3.37 (0.40)	2.77 (0.47)	<0.001
Medical care (single item) (PR)	4.00 (0.00)	3.69 (0.51)	2.83 (0.89)	<0.001
ESRQ	5.49 (11.42)	–5.21 (9.71)	12.71 (15.14)	0.008
Significant Tukey Post Hoc test	QoC: 1>2 and 3 ESRQ: 1>3	QoC: 1>2 >3 ESRQ: 2>3	QoC: 1>2 >3 ESRQ: 1 and 2 >3	

Notes: *P-value describes significant differences between the three clusters measured by ANOVA. Level of significance <0.05. Tukey Post Hoc test: All variables in the clusters differed significantly except Medical–Technical competence between Clusters 2 and 3.

Table 2 Cluster Comparison: Person-Related Conditions (n = 140)

Cluster	1	2	3		
Description	Best Perception Of Care Quality And More Satisfied n (%) 57 (41)	Better Perceptions Of Care Quality And Most Satisfied n (%) 48 (34)	Worst Perceptions Of Care Quality And Less Satisfied n (%) 35 (25)	P*	Tukey Post Hoc Test
Age, mean (SD) Missing	61.89 (10.55) 3	67.47 (12.58) 1	65.66 (10.72) 1	0.061	
Gender, n (%) Female Male Missing	29 (53) 26 (47) 2	23 (49) 24 (51) 1	22 (63) 13 (37) 0	0.443	
Education, n (%) Compulsory school/high school or equivalent University/university college Missing	29 (54) 25 (46) 3	33 (69) 15 (31) 0	21 (64) 12 (36) 2	0.284	
Type of diagnosis, n (%) Malignant illness (cancer)/Mixed malignant and non-malignant illnesses Non-malignant illness (eg, COPD, HF, MS, ALS, Parkinson's disease) Missing	51 (91) 5 (9) 1	39 (81) 9 (19) 0	25 (71) 10 (29) 0	0.052	
Psychological wellbeing, mean (SD) Missing	3.66 (0.82) 0	3.44 (0.94) 0	3.31 (1.12) 0	0.259	
EQ-VAS, mean (SD) Missing	48.06 (19.85) 0	50.91 (21.63) 0	43.06 (17.55) 0	0.239	
SOC, mean (SD) Missing	65.49 (9.98) 7	61.69 (9.64) 3	57.63 (12.38) 2	0.006	1>3
Time in care, n (%) 3–7 days 8–30 days 31–182 days (1–6 months) >183 (6 months) Missing	11 (21) 17 (33) 17 (33) 7 (13) 5	9 (19) 14 (29) 10 (21) 15 (31) 0	3 (9) 9 (28) 9 (28) 11 (35) 3	0.256	
Subjective importance scale QPP-PC, mean (SD)					
Medical–technical competence	3.45 (0.58)	3.03 (0.57)	2.91 (0.66)	<0.001	1 >2 and 3
Physical–technical conditions	3.64 (0.46)	3.51 (0.57)	3.26 (0.58)	0.009	1>3
Identity-oriented approach	3.71 (0.35)	3.40 (0.48)	3.37 (0.51)	0.001	1 >2 and 3
Socio-cultural atmosphere	3.59 (0.38)	3.32 (0.48)	3.27 (0.55)	0.004	1 >2 and 3
Medical care (single item)	3.94 (0.25)	3.80 (0.51)	3.47 (0.62)	<0.001	1 and 2 >3

Notes: *P-value describes significant differences between the three clusters measured by ANCOVA and Pearson Chi-Square Test as appropriate. Level of significance <0.05.

significantly higher in Cluster 1 than patients in Clusters 2 and 3; the dimensions about subjective importance of medical–technical competence of the caregivers, the identity-oriented approach of the caregivers and the sociocultural atmosphere of

the care organization. Patients in Cluster 1 scored statistically significantly higher than patients in Cluster 3 on the dimension about subjective importance of the physical–technical conditions of the care organization, the single item about subjective

Table 3 Cluster Comparison: Organization-Related Conditions (n = 140)

Cluster	1	2	3	
Description	Best Perception Of Care Quality And More Satisfied	Better Perceptions Of Care Quality And Most Satisfied	Worst Perceptions Of Care Quality And Less Satisfied	
n (%)	57 (41)	48 (34)	35 (25)	P*
	n (%)	n (%)	n (%)	
Organizational model for nursing care				0.559
Team nursing	19 (33)	20 (42)	11 (31)	
Primary nursing	38 (67)	28 (58)	24 (69)	
Settings with physicians who have achieved palliative medicine as a subspecialty				0.014
Settings with physicians having subspecialty in palliative medicine	37 (65)	23 (48)	12 (34)	
Settings without physicians having subspecialty in palliative medicine	20 (35)	25 (52)	23 (66)	
Settings of care				0.021
Hospice inpatient care	27 (47)	16 (33)	7 (20)	
Hospice day care	18 (32)	15 (31)	9 (26)	
Palliative care units in nursing homes	8 (14)	9 (19)	7 (20)	
Homecare	4 (7)	8 (17)	12 (34)	

Notes: *P-value describes significant differences between the three clusters measured by Pearson Chi-Square Test. Level of significance <0.05.

importance of the medical care. Patients in Cluster 1 also scored their sense of coherence to be statistically significantly higher compared to patients in Cluster 3.

When comparing the patients in the three clusters regarding the organization-related conditions, statistically significant differences were present regarding whether patients receive care from physicians with subspecialty in palliative medicine and the settings of care. In Cluster 1, proportionally more patients received care from physicians with subspecialty in palliative care medicine and received care in hospice inpatient care, than patients in Cluster 2 and 3.

Cluster 2: Better Perceptions Of Care Quality – Most Satisfied

Patients in Cluster 2 represented 34% of the respondents and had “better perceptions of care quality and were most satisfied”. Patients in this Cluster 2 scored statistically significantly lower than patients in Cluster 1 and higher than patients in Cluster 3 on all care quality dimensions (perceived reality scale) and single items. Satisfaction was scored statistically significantly higher than for patients in Cluster 3.

Person-related conditions: Patients in this cluster scored statistically significantly lower than patients in

Cluster 1 on the subjective importance scale for the dimensions about subjective importance of medical–technical competence of the caregivers, the identity-oriented approach of the caregivers and the sociocultural atmosphere of the care organization. For the single item about subjective importance of medical care, patients in Cluster 2 scored statistically significantly higher than patients in Cluster 3. Patients in Cluster 2 did not score statistically significantly different than patients in Clusters 1 and 3, regarding their sense of coherence.

Regarding the organization-related conditions, statistically significant differences were present regarding whether patients receive care from physicians with subspecialty in palliative medicine and the settings of care. In Cluster 2, proportionally more patients received care from physicians with subspecialty in palliative care medicine and received care in hospice inpatient care, than patients in Cluster 3 and less than patients in Cluster 1.

Cluster 3: Worst Perceptions Of Care Quality – Less Satisfied

Patients in Cluster 3 represented 25% of the respondents and had “worst perceptions of care quality and were less satisfied.” Patients in this cluster scored statistically

significantly lower than patients in Clusters 1 and 2 on all care quality dimensions (perceived reality scale) and single items except the dimension about medical-technical competence of the caregiver. Satisfaction was scored statistically significantly lower than for patients in Clusters 1 and 2.

Regarding person-related conditions, patients in this cluster scored statistically significantly lower on all of the dimensions on the subjective importance scale and single item than patients in Cluster 1, and lower than Cluster 2 for the single item about subjective importance of the medical care. Patients in Cluster 3 scored their sense of coherence statistically significantly lower than patients in Cluster 1.

Statistically significant differences were present regarding the following organization-related conditions: whether patients receive care from physicians with subspecialty in palliative medicine and the settings of care. Cluster 3 has proportionally fewer patients who received care from physicians with subspecialty in palliative care medicine and received care in hospice inpatient care, than patients in Clusters 1 and 2. More patients in this cluster receive care from homecare.

Discussion

Patients' Profiles Related To Perceptions Of Quality Of Care And Satisfaction

Three unique patient clusters with different patterns of perceptions of quality of care and satisfaction were identified: Cluster 1 where patients had best perception of care quality and were more satisfied, Cluster 2 patients had better perceptions of care quality and were most satisfied and Cluster 3 where patients had worst perceptions of care quality and were less satisfied. Few previous studies have investigated clusters of patients related to their perceptions of care quality and satisfaction, and none has been identified from the palliative care setting. In previous studies, number of clusters identified ranged between 2 and 8 clusters.^{9–11,39,40} However, commonly the clusters represented patients who were very satisfied and perceived the care quality as high, patients who were very dissatisfied and perceived the care quality to be low, and finally, patients who held more average scores. This is in line with the findings in this present study. Previous studies, which used cluster analysis, included patients from general hospital wards^{9,10} specialized hospital wards as postnatal care (women only),³⁹ wards caring for patients with diabetes 1 following transplantation⁴⁰ and non-specialized nursing home wards,¹¹ and must therefore be compared with the findings in this study with caution.

In this present study, the three clusters were relatively equally distributed among patients in each group, but slightly fewer patients in Cluster 3 who were most dissatisfied and scored the care quality to be lowest. Based on this, most patients receiving palliative care in this present study perceived the care quality to be good and were satisfied with their care. This is in line with previous studies from the hospital context that showed a lower proportion of patients who are dissatisfied or perceive the care quality to be lowest.^{9,10,39,40} Most of the patients in this present study were also recruited from an inpatient hospice setting in hospital. Interestingly, in a study from the nursing home context of care, significantly more patients were placed in the cluster who perceived the care quality to be worst (67%).¹¹ The differences may indicate that a higher proportion of patients in specific settings perceive the care quality to be low. But it may also be explained by methodological issues, eg, the determination of number of clusters and cut-off values of quality scores within each cluster. Previous studies using the QPP instrument have defined high scores on QPP items ranging from about 3.30 to 4.0. Scores ranging between 3.30 and 3.00 are considered a modest rating, and from 3.00 and lower considered low-quality rating.^{41–43} Studies using other instruments may interpret scores clusters differently.

One might expect that patients who perceive the care quality to be high also are most satisfied and those that had the worst perception of the care quality to be less satisfied. For Cluster 3, this assumption was met. However, a previous study and this present study have shown that this assumption may not be correct for all patient profiles.⁹ Interestingly, patients' perceptions of care quality did not correlate with patients' satisfaction for Clusters 1 and 2. This means that patients who perceive the care quality to be best were not necessarily most satisfied with the care. The difference between patients' satisfaction in Clusters 1 and 2 was not statistically significant in this study, but the finding is supported by a previous cluster study from the hospital setting.⁹ One may conclude that the relationship between patients' perception of care quality and patients' satisfaction is more complex and need to be further investigated. It also may be interpreted that patient satisfaction and perceptions of care quality should be equalized with caution.

Characteristics Of The Patients' Profiles

Patients in Clusters 1 and 2 had best or better perceptions of care quality and were most or more satisfied than patients in Cluster 3. The clusters were characterized by

person- and organization-related conditions. Patients in Clusters 1 and 2 were characterized by higher scores on perceptions of subjective importance and sense of coherence (person-related conditions), and receiving specialized care from physicians that were specialist in palliative care (organization-related conditions), than patients in Cluster 3. Few previous studies have investigated what characterizes patients in the different clusters, but one study has shown that patients in clusters that had better perceptions of care quality and were more satisfied were characterized by higher scores on the sense of coherence scale,⁹ and another study showed that clusters with high satisfaction were associated with better psychosocial adjustment and less psychological distress.⁴⁰ This is also in line with other studies that have established a positive relationship between high scores of sense of coherence and quality of care and satisfaction.^{14,44,45} Sense of coherence is a general life orientation and comprises how a person can comprehend, manage and find meaning in complex and difficult situations,³⁴ such as being in a palliative phase near the end of life. This finding can be understood as patients who have high scores on the sense of coherence scale manage their situation in a better way due to their life orientation, and that these patients also perceive their care to be of high quality and are more satisfied.

Patients in Cluster 1 and Cluster 2 had significantly higher scores on subjective importance of care aspects (patients' preferences) than patients in Cluster 3. This may be interpreted as patients' perceptions of care received were in line with their preferences for care in the three clusters, which has previously been shown.⁹

The organization-related conditions regarding context of care and physicians' competence also characterized the clusters. Patients in Cluster 1 and Cluster 2 had proportionally more patients who received care from physicians with subspecialty in palliative care medicine and received care from services that provide specialized palliative care services (hospice inpatient care, hospice day care and palliative care units in nursing homes) than patients in Cluster 3. The relationship between perceptions of high care quality and specialized palliative care has previously been shown in the palliative care context.^{13,45–48} This highlights and supports the need for specialized palliative care services and specialized training for healthcare personnel in palliative care.

Patients in Cluster 3 had the worst perceptions of care quality and were less satisfied. Compared to patients in Clusters 1 and 2, patients in Cluster 3 were characterized

by having: lower perceptions of subjective importance and lower scores on the sense of coherence scale; they received care from physicians without specialty in palliative care and they received care from services not specialized in palliative care. In line with the discussion for Clusters 1 and 2, the relationship between care quality and patients' low scores of sense of coherence, subjective importance and specialized palliative care and competency have been supported by previous studies.^{9,13,40,44,46–48}

These differences might be explained by person-related conditions in that patients in Cluster 3 scored lower on their sense of coherence and subjective importance of care aspects. This may be interpreted that these patients managed their situation poorly and did not perceive that the care aspects were very important to them. Based on these findings, it is important to identify and pay special attention to this group of patients, and find better ways to care for them. A person-centered care approach involves knowing the patient as a person, placing patients as the center of care and healthcare professionals being respectful and responsive to patients' and families' life situations, preferences, needs and values.^{49,50} This approach has been adapted and used in the palliative care context and a model has been developed to guide multidisciplinary healthcare personnel to work according to this approach.⁵¹ Implementing a person-centered approach in the palliative care may thereby enable personnel to identify patients' life orientation, identify how they manage their situation, identify their preferences for care and what is important to them, and thereby better enable healthcare personnel to tailor care according to these specific group of patients' needs and wishes.

The results for patients in Cluster 3 may also be explained by the context of care, where a lower proportion of patients in Cluster 3 received care from specialized palliative care services, where most received care in the non-specialized homecare context. Since most patients in Cluster 3 were admitted to homecare care context, the findings may be interpreted that palliative training and specialized palliative care services is needed in this specific care context. This study investigated palliative education for physicians. However, palliative care training is needed for all personnel who cares for patients in palliative care, which includes a multidisciplinary staff.⁵² European Association for Palliative Care (EAPC) has developed a framework, which includes three levels of education in palliative care: 1) Education in the palliative care approach in general settings of care, not specialized in palliative care, 2) education in general palliative care for

healthcare personnel who frequently care for patients in a palliative phase and 3) education in specialist palliative care for healthcare personnel who mainly care for patients with complex needs in a palliative phase of their illness.⁵² Education in palliative care thereby should be incorporated in the initial training of all healthcare personnel, and in further training program at advanced levels. Based on the EAPC framework, education at levels 1 and 2 is needed in the non-specialized homecare context. However, homecare services are facing challenges related to more patients with complex needs that require specialist palliative care in their homes. Facilitation of specialized palliative homecare teams has been found to improve patient outcomes and reduce hospital admissions and is recommended as part of the care.⁵³ Such multidisciplinary teams will thereby provide specialist competence at level 3 to patients receiving palliative care at home, and should be part of the palliative homecare. Education at all three levels seem to be important to enhance the care quality and satisfaction with care for patients in homecare.

Previous cluster studies have highlighted the need for more knowledge of what characterizes the patients' clusters to better explain and understand the clusters of patients, to target specific issues and areas for improvement.¹⁰ The present study has contributed to this knowledge, but more studies from the palliative care context are warranted to support the findings of this study.

Methodological Considerations

This study provides the palliative care context with specific knowledge of patients' profiles and what characterizes the patients within these clusters. Validated instruments were used to measure the cluster variables: quality of palliative care, satisfaction and descriptive variables.^{20,23,28,54} The reliability in this present sample was measured using Cronbach's α , and the α values were above the desired level of 0.7 for most instruments and dimensions apart from the dimension PT in the QPP-PC instrument (PR = 0.45, SI = 0.65). However, this dimension comprised only three items and this may have influenced the low Cronbach's α value observed.⁵⁵ Another strength is that the QPP-PC provides specific dimensions of care quality and not only an overall score for care quality. This has previously been highlighted as important to better provide the healthcare settings with specific areas for improvement to tailor improvement initiatives.¹⁰

The selection of person- and organization-related conditions was based on a review of literature and the researchers' knowledge of the field. However, there

might be other variables of relevance to characterize the clusters.

The response rate was 73 percent, which is considered to have strengthened the validity of the present study. Non-response analysis showed that those who chose not to respond did not differ with regard to age or gender, which reduced the threats of sampling bias.⁵⁶

A limitation of this study might be that the data were collected in 2013 and 2014. However, official documents show that there still is a need for quality improvement in palliative care tailored to where it is most needed.⁵⁷ Cluster analysis can be one way of tailoring palliative care quality. A total of 140 patients with complete answers on the cluster variables were included in the analysis. The patient population is in a palliative phase, so it is difficult to achieve a higher number of respondents. However, the number of respondents in each of the three clusters is sufficient.³⁸ The respondents came from four different types of care services, which led to few answers especially from the homecare service, but the patient characteristics show that the results are generalizable when handled with care.

Conclusion And Clinical Implications

One may assume that patients' perceptions of quality of care and satisfaction are positively associated; however, the result shows that this relationship is more complex. The results provide multidisciplinary healthcare personnel with important knowledge about patient profiles and what characterizes them, to tailor quality work initiatives and improve person-centered care for different groups of patients in the palliative care contexts. Healthcare personnel from multiple professions should pay special attention to patients with low sense of coherence (who seem to manage their situation poorly) and who seem to not express preferences for care. Additionally, healthcare improvement initiatives should focus on implementing a person-centered approach, increasing the palliative care competence and training for the multiprofessional staff providing palliative care and facilitate specialized palliative care services, especially in the homecare context.

Abbreviations

ANOVA, analysis of variance; ANCOVA, analysis of covariance; ESRQ, Emotional Stress Reaction Questionnaire; EQ-VAS, EuroQol-visual analogue scale; ID, identity-oriented approach dimension; MT, medical-technical competence dimension; PR, perceived reality; PT, physical-technical conditions dimension; QPP-PC, quality from the

patients' perspective specific to palliative care; RRN, registered nurse responsible for recruiting patients; SC, sociocultural atmosphere dimension; SI, subjective importance; SOC, sense of coherence; QoC, quality of care.

Ethical Considerations And Approval

The study was reported to the Regional Committee for Medical and Health Research Ethics in south-east Norway (REC no. 2013/865) and approved by the Norwegian Social Science Data Services (NSD, no. 34770). Approval for the study to be conducted was obtained from the head administrators of all the settings included. Verbal and written consent for participating in the study was obtained from the patients who were offered an opportunity to withdraw from the study. Information was provided that whether or not a patient decided to participate would have no consequences for their care. Patients had the opportunity to ask about the questions and talk about any emotional aspects that emerged after filling out the questionnaire with the first author (about the questionnaire and the study) and/or the RRN (about emotional aspects). Permission was obtained to use the QPP/QPP-PC, ESRQ, SOC scale and EQ-5D-3L questionnaires.

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Author Contributions

All the authors (TS, BWL and VAG) were involved in developing the design and method. TS performed the acquisition of data. TS, BWL and VAG performed the analysis of data. All authors (TS, BWL and VAG) were involved in the interpretation of analysis. TS and VAG wrote the draft manuscript. All authors (TS, BWL and VAG) contributed to data analysis, drafting and revising the article, gave final approval of the version to be published and agree to be accountable for all aspects of the work.

Disclosure

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