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Patients' sense of support within the family in the palliative care context: what are the influencing factors?

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Abstract

***Objective*: Mutual support within the family is of great importance to maintain its proper functioning. The study aim, which was based on a family system approach, was to evaluate which variables are associated with patients' sense of support within the family in the palliative care context.**

***Methods*: We recruited 174 adult patients (65% of those eligible) from six palliative home care units, who had non-curable disease with an expected short-term survival, such as disseminated cancer or non-malignant diagnosis. The relationship between the endpoint and individual factors were evaluated in a stepwise model-building procedure using generalised linear model (ordinal multinomial distribution and logit link).**

***Results*: The respondents' ratings of their sense of support within the family ranged from 1 (never) to 6 (always), with a mean value of 5.2 (standard deviation 1.06). Patients who less frequently sensed family support experienced more often stress, worry about their private economy, lower self-efficacy, lower sense of security with palliative care provided (lower ratings on subscales of care interaction, mastery and prevailed own identity), more often anxiety, less often perceived general well-being for closest ones and less often sense of support from more distant family members. In the model building, three variables were selected to predict the patients' sense of support within the family.**

***Conclusions*: The dying patients' sense of support within the family related to several factors, and these may help the palliative care teams to identify patients at risk and to alleviate suffering, for example, through supporting the closest family members.**

Introduction

Suffering often emerges with impending death and presents a crisis and a challenge not only to the ill individual but also to the entire family [1–5]. The family members may be burdened by the situation, but they also constitute the potential source of support that can ameliorate the ill person's suffering [5,6].

Mutual support within the family is of great importance to its proper functioning. For example, Kissane *et al.* developed five classes of typologies on the basis of one member's perceptions of his or her family's cohesiveness, expressiveness and conflict resolution. Two types of families appeared well functioning, that is, supportive and capable of resolving conflict. The supportive family was characterised by high levels of mutual support and cohesion and exhibited low levels of psychosocial morbidity among their members [6,7]. In contrast, sullen, hostile and intermediate family types were significantly associated with progressively increasing levels of distress and poor social adjustment [6]. Other studies in a palliative care or advanced cancer context have suggested that the patients' social well-being, including support within the family, is of importance, for example, as a significant contributor to the overall quality of life [8,9], and that lack of support from family and friends or conflictual social support may be a powerful risk factor for morbidity [10,11].

Although the importance of the family support to the individual patient is well grounded in the palliative care literature, the theoretical foundation in such research area is sparse [3,12]. Family system theory is one theoretical standpoint that explains the individual's situation in relation to the family and its wider context. This theory suggests that the family should be seen as both an interrelated and an interdependent individual part within a hierarchy of subsystems and suprasystems [13]. The theory postulates the following: (i) a change in one family member will have an impact on the entire system; (ii) a family system is one element of a larger suprasystem; and (iii) the family system is composed of many subsystems [4]. Communities, the healthcare system, the educational systems and also a palliative care unit have all been suggested as possible suprasystems to which the family may belong [3]. Within a family system, there are often many subsystems, and two or more family members who interrelate can form a subsystem, for example, sibling, parental and spousal subsystems may exist within a family system. Furthermore, each family member may be part of a variety of different subsystems. Although a family system approach is used in couple and family therapy in palliative care and cancer care, a recent systematic literature search and narrative review have found that such an approach has not been sufficiently tested for effectiveness in patient–family care pairs in that particular context [12].

Despite the evidence emerging in the palliative care context that illuminates the importance of patients having a sense of support within the family [6,8,10,11] and the development of theories, such as a family system theory that suggests an approach towards understanding the importance of such support within the family [3], there is a lack of theoretically grounded studies that report on the aspects associated with patients' sense of support within the family during palliative care. To improve palliative care and to help reduce patients' suffering, it is important to determine which aspects are associated with the patients' sense of support within the family to enable practitioners to identify individuals at risk and to plan a course of action.

Goals

On the basis of a family system approach, the goals of the present analysis were to evaluate which variables are associated with patients' sense of support within the family in the palliative care context and to develop a model that predicts patients' sense of such support.

Main hypotheses

We wanted to frame our analyses with the family system theory. To be able to test the hypotheses listed later, we made the following assumptions on the basis of the family system theory (see earlier discussion): (i) the patients' sense of support within the family was an indicator of the *subsystem Patient-Closest family*, that is, the relationship between the patient and the family members the patient had more emotional closeness to, and that this subsystem was important to the family functioning; (ii) a change in one part of the subsystem Patient-Closest family—that is, patient or closest family member—would have an impact on the other part of the subsystem; and (iii) a change in the subsystem Patient-Closest family would have an impact on another subsystem, namely *Patient-Other more distant family members* and the *suprasystem Patient-Palliative care unit*.

We hypothesised that the patients' sense of support within the family (as an indicator of subsystem Patient-Closest family), in a population considered to be dying during the coming months, would be related to the following four domains:

- *The patient characteristics*: in terms of demographics (e.g. female gender and older age), diagnosis (e.g. having cancer), health-related quality of life, symptom intensity (inverse relationship), perceived stress (inverse relationship), coping, self-efficacy and attachment security, as an indicator of the subsystem Patient-Closest family.
- *Closest family general well-being*: in terms of the patient's perception of the closest family general well-being, as an indicator of the subsystem Patient-Closest family.
- *Other family members' support*: in terms of the patient's perception of support from other members of family and friends than the 'closest family', as an indicator of the subsystem Patient-Other more distant family members.
- *Palliative care unit security*: in terms of the patients' sense of security in the care provided by the palliative home care unit, as an indicator of the suprasystem Patient-Palliative care unit.

These hypotheses were based on previous findings in the literature, which suggested that the patients' sense of support within or from the family, when they were admitted to palliative care or diagnosed with advanced cancer, is associated with gender [14], socioeconomic status [14], cultural diversity [14], psychosocial morbidity in both the patient and the family [10,15,16], attachment anxiety and attachment avoidance [17] and health-related quality of life [8,9]. Additionally, we hypothesised that older age, having cancer, symptom intensity, coping, self-efficacy, worry about personal finances and perceived quality of the received palliative care would be associated with the patients' sense of support within the family because these aspects have also been reported to be important in relation to palliative care or in cancer care [1,12,18–23]. A theoretical conceptual description of the hypothesised relationships, where central concepts and assumptions in family system theory were applied to the palliative care context (see earlier discussion), is presented in Figure 1 (this conceptual description was developed by the authors prior to the study.

Material and methods

Participants, eligibility and procedure

The participants were recruited from six palliative home care units. Three of the units were advanced palliative home care teams (with a multiprofessional team that included a physician, 24-h services and access to a backup ward) and three were primary-care-based teams with a palliative care consultant and a specialist nurse available during the daytime.

The patients were all in the palliative stage of their disease; diagnosed with a non-curable disease, an expected

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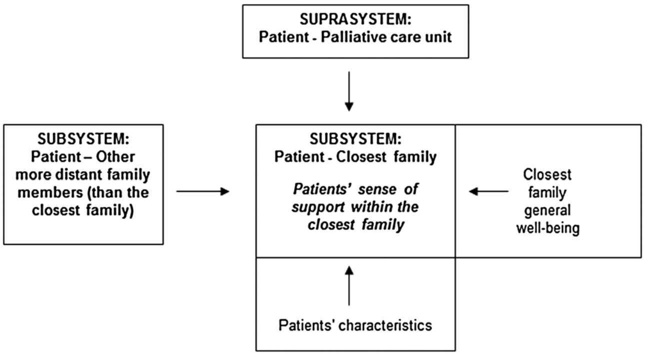

Figure 1. Conceptual description of the hypothesised relationships between patients' perception of support within the closest family (endpoint) and the following explanatory domains: Patients' individual characteristics, Closest family general well-being, the subsystem Patient-Other family members and friends than the closest ones and the suprasystem Patient-Palliative care unit. Arrows are unidirectional to reflect the approach of analyses (rather than the causality of possible relationships)

short-term survival, disseminated cancer or non-malignant diagnosis (e.g. severe heart failure, severe lung disease or lethal neurological diseases); and older than 18 years. We excluded from the study those patients who had cognitive failure, suffered from confusion, were too weak to participate, had speaking or hearing problems and were unable to speak and understand Swedish.

The staff members of the palliative care team assessed the inclusion and exclusion criteria for all of the patients who were admitted to the participating palliative units. The eligible participants received written study information and were asked by a staff member of the palliative care team if they wanted to participate; the patients were assured confidentiality and their right to decline at any time without giving any reason. The five interviewers were staff experienced in palliative care but not involved in the interviewee's medical care. Most of the patients (91%) preferred a telephone interview. The data were collected between September 2009 and October 2010. The research Regional Ethics Committee approved this study (Dnr: 144–06).

During the data collection, 403 patients were admitted to the participating palliative care units. A total of 136 patients (34%) were excluded from the study because of cognitive failure or confusion ($n = 47$), weakness ($n = 47$), speaking or hearing problems ($n = 22$), inability to speak and understand Swedish ($n = 11$) and other reasons ($n = 9$). In sum, 267 patients (66%) were eligible to participate in the study. Of those 267, a total of 199 patients (58% women and 42% men) agreed to participate in the study, and 174 patients were interviewed (58% women and 42% men). The causes for dropping from the interview were as follows: eight patients died in the period between giving consent and the scheduled interview; 13 patients were no longer able to participate because of deteriorating health; two patients no longer wanted to participate; and two did not participate for other reasons. Compared with the patients who were interviewed, the patients who declined participation were older (mean 75.5 vs. 68.9 years; $p < 0.01$) but were similar in terms of gender (95% confidence interval (CI) for OR, 0.684–2.11) and main diagnoses (95% CI, 0.332–3.51).

The individuals who had not responded to the question about their sense of support within the closest family in the palliative care context ($n = 9$) were removed from the study, leaving a sample of 165 participants (participation rate: 61.8%; 165/267). The characteristics of these 165 participants are presented in Table 1.

Measures

Dependent variable

The patients' sense of support within the family in the palliative care context (endpoint) was measured by one question developed by the authors (six-point response scale (1 = never to 6 = always)). We wanted to avoid excluding single patients without a traditional nuclear family; therefore, we decided to use a broad definition of a family [3] and let the patients themselves choose which subsystem was the most important by phrasing the question without the word 'family' but instead asking 'How often do you and your closest ones give support to each other?'

Independent variables in four domains

The four domains potentially important to the endpoint were evaluated by the following variables:

- *Patient characteristics* (subsystem Patient-Closest family): *Demographics*, such as age, gender and marital status, were collected from the medical records by the palliative care team. Education, living and family conditions, and country of birth were assessed in the interview. *Diagnosis* was collected from the palliative care team, and time since diagnosis was assessed during the interview. *Health-related quality of life* was measured by the EuroQol-5D, which is a valid and reliable tool for measuring health-related quality of life. The instrument comprises five domains: mobility, self-care, pain, usual activities and psychological status (answers categories: no/some/severe problems). An index score was calculated for each respondent's health status (1 = full health; −0.594 = worst imaginable health state) [24]. One general question of quality of life from the World Health Organization Quality of Life Assessment 100 instrument was used (a five-point scale (1 = very poor; 5 = very)) [25]. To measure health, one overall question (a five-point

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scale (1 = excellent health to 5 = poor)) was used in the questionnaire SF-36, which is a 36-item short form health survey questionnaire [26]. *Symptom intensity* was measured by the Edmonton Symptom Assessment System [27], which is a validated self-reporting tool to measure the severity of common symptoms in patients with advanced incurable illness. It includes nine common symptoms of advanced cancer (pain, tiredness, nausea, depression, anxiety, drowsiness, shortness of breath, appetite and well-being; 11-point numerical rating scales (0–10) with higher scores representing the worse symptom intensity). In the present study, we did not use the optional 10th question about a patient-specific symptom (selected by the patient). An index score (mean value of the patient's scoring of the nine symptoms) was calculated. *Attachment security* was assessed using the 16-item Experiences in Close Relationships scale [28] to measure the attachment anxiety (fear of rejection and abandonment) and avoidance (discomfort with closeness and dependence on close others) in close relationships (including non-romantic partners). This is a seven-point numerical rating scale (1–7) with higher scores on each of these dimensions representing greater attachment insecurity. *Stress* was assessed using two (of 10) items from the Perceived Stress Scale [29] (a five-point scale (0 = never to 4 = very often)). A question concerning *Worry about private economy* during the last month was constructed by the authors (a five-point scale (0 = never to 4 = very often)). *Self-efficacy* was measured using one statement (of 10) from the General Self-Efficacy Scale (a four-point scale (1 = not at all true to 4 = exactly true)) [30,31]. A statement concerning *religious or existential belief that helps* the informant to cope with problems was constructed by the authors (a four-point scale (1 = not at all true to 4 = exactly true)).

- -*Closest family general well-being* (subsystem Patient-Closest family): The patients' perception of the closest family members' general well-being was assessed by a broad question constructed by the authors ('How often during the palliative home care period have you perceived that your closest one/ones experiences/experience general well-being?'; six-point response scale (1 = never to 6 = always)). For the respondent, the context of the question was clearly in relation to his or her situation with severe illness and admittance to the advanced palliative care unit, and the expression 'general well-being' refers to overall comfort, both physical and psychological (in a Swedish context, the question would not involve, e.g. economic well-being).
- *Other family members' support* (subsystem Patient-Other more distant family members): The patient's sense of support from other members of the family, relatives and friends than the 'closest ones' was assessed by a question developed by the authors (a six-point response scale (1 = never to 6 = always)).
- *Palliative care unit security* (suprasystem Patient-Palliative care unit): *The patients' sense of security with palliative care* was measured by the Sense of Security in Care instrument for Patients (SEC-P), which is a valid and reliable 15-item instrument (a six-point scale (1 = never to 6 = always); Cronbach's alpha 0.85). SEC-P was developed in palliative home care and possesses a three-component structure: *Care interaction* (eight items; Cronbach's alpha 0.84), *Identity* (four; 0.77) and *Mastery* (three; 0.69) [32]. *Time from admission to the palliative home care services* (collected by staff from the data retrieved from medical records) to the interview was calculated.

In the selection of questions and instruments, we considered the patients' deteriorating health and energy; consequently, short scales or single questions were preferred if possible.

Statistical analyses

The data were analysed using STATISTICA, version 10 (Statsoft Inc., Tulsa, OK, USA). An examination of missing data did not reveal any systematic patterns, and the number of missing values were small, ranging from 5.2% (9/174; on dependent variable) to 14.4% (25/174; on the question regarding patients' concern about their private finances). Where there were missing values, the specific analysis was run without this respondent's information, although the respondent could be included in other analyses.

A few response alternatives were rarely used by respondents and therefore not meaningful to include in the analyses (e.g. there was only one participant who had responded 'never' on the dependent variable). In such cases, the response alternatives were merged with the next alternative.

The variables considered for entry in the analyses were determined to be continuous, with the exception of gender, marital status, living conditions (alone/with husband, wife or cohabitant/with children), having children, country of birth and diagnosis.

Descriptive statistics were calculated for the individual variables in the four domains. The relationship between the dependent variable and the independent variables in the four domains were evaluated by Wald values derived from the generalised linear model analysis with ordinal multinominal distribution and logit link.

In the model-building analyses, Akaike information criterion (AIC) was used [33]. AIC offers a relative measure of the

Table 1. Sample characteristics ($n = 165$) and analysis of the individual variables in relation to the patients' sense of support within the closest family (response variable)

Variable domain (related subsystem or suprasystem)	Variable (range of response alternatives/index)	% responses	Description (mean [SD]; range) or percent	Wald values[a] for individual variable	Relationship
Patient characteristics (subsystem Patient-Closest family)					
Demographics	Gender: male/female	100	57%/43%	1.64	
	Married or partner/ single	100	71%/29%	0.18	
	Living conditions				
	Alone	94	32.2%	0.61	
	With husband, wife or cohabitant	99	68.1%	0.24	
	With children	94	7.7%	2.01	
	Have children	100	92.7%	0.09	
	Native born in Sweden	99	92.7%	0.40	
	Age (in years)	100	68.9 [12.8]; (36–94)	2.89	
	Education (highest level completed) (1–6)	100	3.63 [1.54]; (1–6)	0.67	
	1 (No formal education)		4.2%		
	2 (Basic education only)		27.9%		
	3 (High school)		15.8%		
	4 (Vocational education)		23.6%		
	5 (University <3 years)		3.6%		
	6 (University 3 years or more)		18.8%		
Illness-related	Malignant diagnoses				
	Gastrointestinal	100	32.8%	0.02	
	Respiratory	100	9.1%	4.03	neg.
	Breast	100	12.1%	1.66	
	Gynaecological	100	7.3%	0.62	
	Urological	100	18.2%	2.97	
	Malignant melanoma	100	4.2%	0.02	
	Haematological	100	5.4%	0.36	
	Other malignancies	100	1.2%	2.52	
	Non-malignant diagnoses[b]	100	6.7%	0.03	
	Time since diagnosis (months)	99	33.7 [43.6]; (1–240)	0.01	
Health-related quality of life	EQ-5D index (–0.594 (worst possible) to 1.00 (best possible))	94	0.49 [0.35]; (−0.59 to 1.00)	0.17	
	Mobility (1 (no problems) to 3 (severe problems))	94	1.79 [0.60]; (1–3)	0.05	
	Self-care (1 (no problems) to 3 (severe problems))	95	1.33 [0.58]; (1–3)	0.71	
	Usual activities (1 (no problems) to 3 (severe problems))	95	1.87 [0.72]; (1–3)	0.21	
	Pain/discomfort (1 (no problems) to 3 (severe problems))	95	2.01 [0.61]; (1–3)	0.49	
	Anxiety/depression (1 (no problems) to 3 (severe problems))	95	1.63 [0.59]; (1–3)	1.63	
	General health (1 (excellent) to 5 (bad))	93	3.96 [0.86]; (1–5)	2.85	
	Quality of life (1 (very bad) to 5 (very good))	93	3.25 [1.0]; (1–5)	0.13	
Symptom intensity	ESAS index (0 (none) to 10 (worst possible))	92	2.58 [14.05]; (0–6.5)	1.05	
	Pain (0 (none) to 10 (worst possible))	92	2.41 [2.39]; (0–10)	0.24	
	Tiredness (0 (none) to 10 (worst possible))	92	4.62 [2.66]; (0–10)	0.00	
	Nausea (0 (none) to 10 (worst possible))	92	1.26 [2.21]; (0–10)	0.62	
	Depression (0 (none) to 10 (worst possible))	92	2.00 [2.33]; (0–10)	1.65	
	Anxiety (0 (none) to 10 (worst possible))	92	2.22 [2.34]; (0–10)	11.10	neg.
	Drowsiness (0 (none) to 10 (worst possible))	92	3.7 [2.72]; (0–10)	0.10	

	Shortness of breath (0 (none) to 10 (worst possible))	92	2.39 [3.11]; (0–10)	0.00	
	Appetite (0 (none) to 10 (worst possible))	92	3.55 [2.79]; (0–10)	0.30	
	Well-being (0 (none) to 10 (worst possible))	92	3.63 [2.29]; (0–10)	2.36	
Attachment security	Anxiety dimension (1–7)	93	2.62 [1.02]; (1.00–5.38)	1.90	
	Avoidance dimension (1–7)	94	2.97 [1.16]; (1.00–5.88)	1.09	
Stress and coping	Nervousness and stress (1 (never) to 5 (very often))	93	2.44 [1.07]; (1–5)	4.50	neg.
	Too many problems to manage (1 (never) to 5 (very often))	92	2.09 [1.06]; (1–5)	7.52	neg.
	Worry about private economy (1 (never) to 5 (very often))	90	1.63 [1.07]; (1–5)	8.53	neg.
	Self-efficacy (1 (fully disagree) to 4 (fully agree))	92	3.3 [0.70]; (1–4)	2.50	
	Religious or existential belief that helps (1 (fully disagree) to 4 (fully agree))	92	2.44 [1.21]; (1–4)	4.13	neg.
Closest family general well-being (subsystem Patient-Closest family)	General well-being for closest ones (1 (never) to 6 (always))	100	4.54 [1.16]; (1–6)	27.69	pos.
Other family members' support (subsystem Patient-Other more distant family members)	Support from other family members, relatives or friends (1 (never) to 6 (always))	100	4.95 [1.20]; (2–6)	17.28	pos.
Palliative care unit security (suprasystem Patient-Palliative care unit)	Care interaction subscale (1 (never) to 6 (always))	99	5.14 [0.65]; (2.75–6.00)	31.51	pos.
	Mastery subscale (1 (never) to 6 (always))	100	4.28 [1.06]; (1.00–6.00)	6.09	pos.
	Identity subscale (1 (never) to 6 (always))	100	4.93 [0.82]; (2.50–6.00)	15.42	pos.
	Time from admittance to palliative care unit (days)	97	193 [265]; (3–1954)	0.04	

SD, standard deviation; EQ-5D, EuroQol-5D; ESAS, Edmonton Symptom Assessment System.

[a] Wald = 4 is approximately equivalent to $p = 0.05$; Wald = 6 is approximately equivalent to $p = 0.01$.

[b] Neurological disease ($n = 5$), heart or lung disease ($n = 4$) and others ($n = 2$).

information lost when a given model is used to describe reality. The simplest effective model with the smallest information loss when predicting the outcome gives the lowest AIC value.

First, in the model building, one analysis per domain was conducted, and its AIC was used to decide in which order the domains should be added in the forthcoming stepwise procedure. Only variables with Wald values >2 were allowed to be tried in the further model building. This Wald value corresponds to approximately $p < 0.15$; hence, a generous selection criterion was chosen to reduce the risk of discarding variables that in the further model building would have been useful. All subsequent steps in the model building were performed using the best subset analyses with AIC. Second, the domain with the lowest AIC started the best subset analyses, and the domain with the highest AIC was taken last, because a lower AIC value indicates a higher value of explanation. Classification of the developed model was computed, and the percent correct classifications of the observed cases were calculated. Statistical tests were two-tailed with alpha set at 0.05.

Results

The respondents' ratings of their sense of support within the closest family in the palliative care context ranged from 1 (never) to 6 (always), with a mean value of 5.2 (standard deviation 1.06).

Variables related to endpoint variable 'Sense of support within the closest family'

The analysis of the individual variables showed that all hypothesised domains were significantly related to the endpoint variable (Table 1).

The variables that were positively related to the endpoint dependent variable were as follows: General well-being for closest ones; Support from other family members, relatives or friends (than the Closest family); Care interaction subscale; Identity subscale; and Mastery subscale (Table 1).

The variables that were inversely related to the endpoint variable were as follows: Respiratory malignancy; Anxious subscale; Patient being nervous and feeling stressed; Too many problems to manage; Worrying about private finances; and Religious or existential belief that helps (Table 1).

Model building

The model building started with one analysis per domain (step 1 in Table 2), except for the Patient characteristics domain (step 0 in Table 2). The variables in the latter domain were considered too many, compared with the number of respondents, to be computed simultaneously. Therefore, in step 0, the variables in this domain were

Table 2. Step-wise analyses (Best subset) for prediction of patient's sense of support within the family (subsystem Patient-Closest family) in the palliative care context

			Wald value for partial regression coefficients				
Variable domain	**AIC**	**Variable**	**Step 0**^{b}	**Step 1**	**Step 2**	**Step 3**	**Step 4**
Palliative care unit security (suprasystem Patient-Palliative care unit)	343.29	Care interaction subscale (1 (never) to 6 (always))		19.81	25.30	30.49	21.26
		Mastery subscale (1 (never) to 6 (always))		~~0.61~~	~~0.20~~		
		Identity subscale (1 (never) to 6 (always))		5.32	~~0.18~~		
		Time from admission to palliative care unit (days)		~~0.68~~			
Patient characteristics (subsystem Patient-Closest family)	349.07						
Stress and coping	346.08	Nervousness and stress (1 (never) to 5 (very often))	~~0.54~~				
	Step 0	Too many problems to manage (1 (never) to 5 (very often))	2.11	3.41	~~1.92~~		
		Worry about private economy (1 (never) to 5 (very often))	3.46	3.26	3.12	~~0.93~~	
		Self-efficacy (1 (fully disagree) to 4 (fully agree))	~~0.063~~				
		Religious or existential belief that helps (1 (fully disagree) to 4 (fully agree))	4.02	3.52	3.05	2.81	~~1.64~~
Health-related quality of life	365.13	EQ-5D index (–0.594 (worst possible) to 1.00 (best possible))	~~1.11~~				
	Step 0	General health (1(excellent) to 5 (bad))	4.37	~~0.21~~			
		Quality of life (1(very bad) to 5 (very good))	~~0.32~~				
Symptom intensity	366.9	ESAS index (0 (none) to 10(worst possible))	~~1.05~~				
	Step 0						
Attachment security	371.05	Anxiety dimension (1–7)	~~1.40~~				
	Step 0	Avoidance dimension (1–7)	~~0.51~~				
Demographics	375.85	Gender: male/female	~~0.59~~				
	Step 0	Married or partner/ single	~~0.170~~				
		Living conditions					
		Alone	~~0.145~~				
		With husband, wife or cohabitant	~~0.328~~				
		With children	~~0.53~~				
		Have children	~~0.057~~				
		Native born in Sweden	~~0.53~~				
		Age (in years)	~~0.32~~				
		Education (highest level completed) (1–6)	~~0.94~~				
Illness-related	393.18	Malignant diagnoses					
	Step 0	Gastrointestinal	~~0.26~~				
		Respiratory	~~1.47~~				
		Breast	~~0.79~~				
		Gynaecological	~~0.73~~				
		Urological	~~0.015~~				
		Malignant melanoma	~~0.22~~				
		Haematological	~~0.064~~				
		Other malignancies	~~0.14~~				
		Non-malignant diagnoses^c	~~0.095~~				
		Time since diagnosis (months)	~~0.14~~				
Closest family general well-being (subsystem Patient-Closest family)	362.70	General well-being for closest ones (1 (never) to 6 (always))		27.70		13.57	14.76
Other family members' support (subsystem Patient-Other more distant family members)	374.69	Support from other family members, relatives or friends (1 (never) to 6 (always))		17.30			5.06

Strike-through indicates variables that were excluded from the following steps.

EQ-5D, EuroQol-5D; ESAS, Edmonton Symptom Assessment System.

[a] Wald = 4 is approximately equivalent to $p = 0.05$; Wald = 6 is approximately equivalent to $p = 0.01$. Only variables with Wald > 2 were selected for further analyses.

[b] The variables in the 'Characteristics of the patient' domain were considered too many, compared with number of respondents, to be computed at the same time. Therefore, in step 0, variables in this domain were divided into subdomains, and Wald values for each subdomain were computed.

[c] Neurological disease ($n = 5$), heart or lung disease ($n = 4$) and others ($n = 2$).

divided into subdomains, and Wald values for each subdomain were computed. Only the variables with Wald 2 were selected for additional analyses in step 1. In total, seven variables were selected in step 1 ($\text{Wald} > 2$) for further model building, and 29 were left out in step 0–1 ($\text{Wald} < 2$). The AIC for the four domains resulted in the Palliative care unit security domain (suprasystem Patient-Palliative care unit) that was added first in the stepwise procedure, and Other family members' support domain (subsystem Patient-Other more distant family members) was added last (Table 2). The stepwise model building resulted in a model with the three following variables (decreasing Wald values): Care interaction subscale, General well-being for closest ones and Support from other family members, relatives or friends than the closest ones (Table 2).

Discussion

We present unique evidence for identifying patients at risk of suffering from lack of support within the closest family in the palliative care context. The results seem to support application of a family system theory framework in clinical practice. Our analysis identified 11 variables that were significantly associated with the patients' sense of support within the closest family, and in the model building, three variables (Care interaction (subscale of SEC-P); General well-being for closest ones; and Support from other family members, relatives or friends than the closest ones) were selected for predicting such sense. Additionally, our results suggest that many patients who are close to death frequently sense support within the family in the palliative home care context.

The patients who less frequently sensed support within the closest family rated more often anxiety, nervousness and stress; having too many problems to manage; more often worry about personal finances; have lower ratings of sense of security with palliative care (in terms of the care interaction, of mastery and of prevailed own identity); rated less often support from family, relatives and friends other than the closest ones; and perceived less often general well-being for closest family members. These findings are supported by previous studies [1,10,12,15,16,18,23] and indicated that the dying patients' sense of support within the family is a complex concept that relates to many other factors in the patient's situation and is of high relevance for palliative care.

Moreover, the patients who less frequently sensed support within the closest family rated stronger agreement with having a religious or existential belief that helps. Although Sweden is a secularised country, this finding was unexpected [2]. Because of the cross-sectional design, one can only speculate about the interpretation: People with limited time remaining to live who do not sense support within the closest family might turn to religious or existential beliefs as a means to cope with the situation, or a religious or existential belief that helps an individual to cope with challenges might hamper the mutual support within the family, for example, if there are different standpoints within the subsystems. Another way to look at the relationship between religious or existential beliefs and family support is that patients who rely on such beliefs may not need and/or seek family support as much.

Previous research has shown that incurable lung cancer is accompanied with patient anxiety [9]. Although such malignancy significantly related in this study to the patients' sense of support within the closest family, there were only 16 patients with such diagnoses in this study population. Therefore, these results should be interpreted with some caution.

The family systems theory suggests that the family should be seen as both an interrelated and an interdependent individual part within a hierarchy of subsystems and suprasystems [4,13]. In the present study, we evaluated the functioning of the subsystem 'Patient and the Closest family', and we assessed whether either of the two domains (Patient characteristics or Closest family general well-being) would be related to the functioning of this subsystem (in terms of the patient's perception of how often the closest family members gave support to each other). This assumption was confirmed in the analyses. Second, we hypothesised that the functioning of either of the two subsystems, Patient-Closest family and Patient-Other more distant family members, would be related to (according to the patient's perception) the functioning of the other. This hypothesis was supported in the analyses. Third, we also hypothesised that the subsystem Patient-Closest family belongs to a suprasystem with the palliative care unit and that the functioning of the suprasystem (in terms of the patient's perception) would be related to the functioning of the specified subsystem. This hypothesis was supported by the data. The results suggest that palliative care services may support the patient and the family functioning through a family system theory approach, which includes seeing the patient as a part of different subsystems and larger suprasystems that are interrelated and interdependent [3,4,13]. In such an approach, it seems important that the palliative care team focus on both the closest family members' situation and the patient's support from the social network outside the closest family.

All three of the subscales (Care interaction, Identity and Mastery) of the newly developed instrument for measuring patients' sense of security in care (SEC-P) were significantly related to the patients' sense of support within the closest family, with the Care interaction subscale and the Identity subscale having some of the highest Wald values (>30 and >15, respectively) of all of the individual variables in the analysis. The Care interaction subscale includes questions about the patient's perception of the availability of the care staff; their ability, attentiveness and knowledge about the patient's situation; and the patient's influence over the care. The provision of such professional support with a family focus may facilitate the patients' sense of security in care and thereby also facilitate the family members' ability to give support to each other.

The Identity subscale includes questions about care placement, feeling secure at home despite care and illness, and the ability to do what is most important. In clinical practice, the support of such dimensions to support the patient's sense of support within the closest family may include care staff planning for care placement together with the patient and the family. The results can also be understood using Hupcey and Morse's definition of social support as a reciprocal support (in contrast to professional support) that 'may be identical (e.g., visiting each other when sick) or vary as a result of the nature of the relationship or severity of an illness (e.g., just smiling and saying "thank you" to the provider when other types of reciprocal support will never be available)' [34]. That is, a patient who can sense that he still has meaningful abilities, despite deteriorating health, may feel that he can contribute to a greater degree in the reciprocal role of supporting the closest family members. In clinical practice, support during palliative care of the patients' sense of still having meaningful abilities may include the provision of suitable aids to help patients (e.g. to manage toilet visits by themselves as long as possible). The care staff may also facilitate open family communication about such identity issues by posing questions to the patient and the family members about individual challenges (that may be unknown to the others)—for example, 'In what way has the disease affected you as individuals? As a family?' Further family discussions about how the family members can support each other in these challenges may be encouraged by care staff probing questions to each individual—for example, 'In what way can the other family members support you with what you find most worrying or challenging?'

Although all of the hypothesised domains significantly related to the patients' sense of support within the closest family in the palliative care context, the results regarding several of the subdomains (demographic, illness-related, health-related quality of life, symptom intensity and attachment security) contrasted to previous studies [8,9,14,17–21].

Limitations

In the study design, we made an assumption that examining one part (the patient's perspective) of a system, which consists of many different yet related parts (different subsystems as well as the palliative care unit as a suprasystem), leads to an accurate depiction of the entire system. Although the patients' perception of the functioning of the different parts is relevant and important *per se*, this design has limitations in generalising one person's perspective to reflect the consensus of the family and should be further studied with data collections from all of the components. In addition, despite a high participation rate (62.9%) for a study of this type in patients with disease at the palliative stage, the participants differed from those who declined to participate and were also most likely the least ill subsample of people receiving palliative care services, and this finding may have consequences on the generalisability of the results to older, single and more severely ill patients. The design was cross-sectional and can therefore only suggest causal relations. Moreover, some limitations of the study relate to measurement validity and reliability. Short questions or single questions were used to minimise participant burden, while obtaining relevant information. Although, most of these variables were selected from valid and reliable instruments, a few were constructed by the authors and had not been tested before, and this may have implications for the interpretations of the results. Finally, the limited range of support within the closest family scores reduces the conclusions that can be made about patients with low scores on this measure.

Conclusion

This study has identified several variables that relate to the patients' sense of support within the family in a palliative care context. We have also presented a model (including the patient's sense (i) of security with the care, especially the Care interaction, (ii) of general well-being for closest ones and (iii) of support from other family members, relatives or friends) that predicts a sense of support within the family. The findings point to the potential value of interventions directed to identify patients close to death who are at risk of suffering from lack of support within the family and to strengthen their sense of such support based on these findings and family system theory.

Future research may seek into also family members' sense of support within the family in a palliative care context, into longitudinal studies, into exploration of the dynamics within the patient–family member dyads and into interventions to enhance patients' sense of support within the family.

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Conflict of interest

The authors have declared no conflicts of interest.

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