Universitätsklinikum Hamburg-Eppendorf

Onkologisches Zentrum
II. Medizinische Klinik und Poliklinik

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Satisfaction with Care and Determining Factors in Family Caregivers of Terminally-Ill Cancer Patients during Specialist Inpatient Palliative Care

Dissertation

zur Erlangung des Grades eines Doktors der Medizin
an der Medizinischen Fakultät der Universität Hamburg.

vorgelegt von:

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aus Hamburg

Hamburg 2021

**Angenommen von der
Medizinischen Fakultät der Universität Hamburg am:
01.04.2022**

**Veröffentlicht mit Genehmigung der
Medizinischen Fakultät der Universität Hamburg.**

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1. Introduction

Through the combination of ongoing breakthroughs in modern medicine and the rising age of the population overall, especially in developed countries [35], the number of oncological patients with long time care needs increases steadily [44, 45]. While medical improvements can prolong a patient‘s life, not all can be cured and some will die of their illness. Patients suffering from incurable and life limiting illnesses have complex needs and often experience psychological as well as physical symptoms. Most palliative patients are cared for solely or in large parts by a family caregiver, e.g. a spouse, child, parent, other relative or close friend [4], often with little or no prior preparation or professional training [12, 36]. They assist not only in day to day routines but also in disease management decisions and support the correct administration of medication [19, 24]. Ideally help is provided to family caregivers and their terminally ill family member as unit of care [11] by specialised palliative care services visiting their homes regularly and when needed [21]. So far much existing palliative care research has been focussed on the person fallen ill and their needs of support during informal or specialised at home, outpatient or inpatient care. However, in palliative care, the family caregivers are also considered an existential part of the unit of care [40]. As established palliative care services do not yet cover the growing calls for specialised palliative outpatient care many family caregivers face their daily challenges alone [24]. Due to an increased burden of care as the primary caregiver family caregivers are more likely to experience psychological and physiological symptoms [13], as well as premature death compared to the general population [23, 38]. While the challenges of at home palliative care may be resolved by the patient‘s death, post-loss burden can be equally as challenging for the bereft family caregivers. Negative emotions like loss, grief and regret replace the daily caregiving routines and pose new threats to family caregivers‘ mental and physical health. In other words, health risks for caregivers continue even after patient death. Comprehensive care, covering patients as well as their caregivers, is the basis of good palliative care [11, 39]. Terminally ill patients can receive specialised palliative care either at home, hospital or hospice. The services provided include help with daily routines, symptom crises and specialised end-of-life care [15, 37].

Over the last two decades research of the development and practice of palliative care [48] in Germany has increased. Between 2012 and 2017, the number of people in Germany with an Advanced Health Care Directive (AHCD) has almost doubled [2]. AHCDs are legally binding directives given by individuals detailing their wishes for diagnoses and treatment options for future illnesses (particularly end-of-life illness). They may include instructions about life-extending treatments and care at the end-of-life [3]. Recent public and political discussions about palliative care (at home and in hospital or hospice) have helped raise awareness about AHCDs and their benefits, especially in a palliative care setting where individuals are not always able to communicate their needs and wishes. Growing public and political interest in palliative care is not only reflected in the increasing number of people with AHCDs, but also in the rising need for good quality palliative care. With longer life expectancy and rising cancer incidence, the demands for palliative care also increase [10]. To ensure best possible palliative care and the future funding of it by the authorities responsible, good research is key. German palliative care guidelines for individuals with terminal cancer recommend patient-reported outcome measurements, such as the Integrated Palliative Care Outcome Scale (IPOS, measures palliative care outcomes including physical and psychological symptoms), to improve palliative care [1]. Patient-reported outcome measures, when used correctly, offer the opportunity to combine clinical assessment with visualisation of patients' needs [9] and therefore appropriate intervention. However, as it can be difficult to assess individuals with advanced illness due to deteriorating mental status [32, 42] it is increasingly important to take account of proxy assessment by family caregivers or staff. As part of a study group investigating different aspects of specialised inpatient palliative care this study aimed to explore the acceptance of, and satisfaction with, interventions offered to family caregivers of inpatients with terminal illness.

It may seem controversial to ask about satisfaction with care as the outcome of palliative medicine, especially end-of-life care, is death rather than recovery. However, satisfaction with care has been identified as an important predictor of quality of care [17]. High satisfaction with care leads to better treatment adherence, continuity with health care providers, and can positively influence health service use by predicting patient behaviours towards its utilisation [17]. Therefore, exploring ways to improve family caregivers' satisfaction with palliative care could lead to improvements in quality of care provided to the patient-family caregiver-unit. There is limited research concerning factors influencing caregivers' satisfaction with care in a specialist inpatient palliative care setting [51]. However, care outcome measures can be used to improve satisfaction with care and palliative care outcomes (such as symptom management, intervention efficacy and level of psychological support) [7], allowing detailed analyses, and national and international comparison of different models of palliative care. Care outcome measures can also identify interventions aimed at improving satisfaction [7], thus improving patient care and quality of life until the end of life.

Therefore, this study will explore caregiver care outcome and satisfaction with palliative care in a specialist palliative care unit, in order to offer insights into family caregivers' characteristics, determining factors of satisfaction with care and good palliative care outcome and implications for future research and the development of interventions in specialist palliative care.

1.1 Aims and Objectives

The overall aim is to explore proxy-reported care outcome and caregiver satisfaction with in-patient palliative care on a specialised palliative care unit. Specific objectives were:

1. To explore caregivers' evaluation of their terminally-ill relative's mental and physical health, and whether these are different based on family caregiver's age, sex, relationship to the patient, education, length of time since patient's terminal diagnosis, anxiety, or depression.

2. To explore family caregiver’s satisfaction with the specialist palliative care provided to their terminally-ill relative in an in-patient setting.
3. To identify variables predicting family caregiver’s satisfaction with specialist palliative care to evaluate the impact of daily clinical practice.

Previous studies conducted to examine possible predictors of satisfaction with care outcomes have identified sociodemographic characteristics like age, sex, marital status and education to be considered [20]. We hypothesised that satisfaction with care and palliative care outcome at the beginning of SIPC both would be high overall and expected to see evidence of differences amongst family caregiver and patient relationship groups as defined for our analysis.

2. Methods

2.1 Study design

The study was designed as non-invasive, questionnaire based cohort study. Ethics commission approval was sought and received prior to data collection. We collected data from two Specialist Inpatient Palliative Care (SIPC) units with comparable approaches to palliative care at the University Hospitals in Hamburg and Goettingen. Both cities represent different areas of the country and parts of the German population: Hamburg being a large metropolis in the north and Goettingen being a smaller, rural town in the middle of Germany. All factors were included in this studies’ analyses. As part of a study group on SIPC it has so far generated doctorates theses as part of a medical degree, as well as presentations at palliative care and interdisciplinary conferences. Research articles on family caregivers’ psychological burdens [40] and predictors of family caregivers’ symptoms and quality of life [41] based on the study groups’ data have also been published.

2.2 Study population

We recruited family caregivers of inpatients with a terminal oncological illness over a 12-month period between June 2016 and July 2017. Data was collected within the first 72 hours of the patients’ admission to the SIPC unit. To be eligible for inclusion, the family caregiver had to be at least 18 years old; and their ill relative had to be an inpatient with a terminal cancer diagnosis who was unlikely to die imminently. Family caregivers were not eligible for inclusion if: their relative was discharged within 24 hours of admission; their ill relative did not want them to participate; staff were unable to establish contact within 72 hours of the patients’ admission; there was a language barrier; the caregiver held legal guardianship only; the palliative care team judged that the psychological burden was too high; or the relative had a cognitive impairment or dementia. Family caregivers were contacted personally by trained study personnel in the SIPC unit and evaluated for participation. After providing written informed consent, participating family caregivers were given the questionnaire with a stamped return-envelope. A single reminder, in person or via telephone, was issued to caregivers who did not return their questionnaire within two working days. Family caregivers were encouraged to contact the palliative care team or trained study personnel immediately if they had any problems or questions about the study to prevent potential study-induced burden and drop-out.

2.3 Measurements

We used four tools to collect data from family caregivers. Two to measure outcome measures and two to assess family caregivers' mental health (summarised in Table 1).

Table 1: Overview of measurement tools used for this study measuring outcome or family caregivers' characteristics, including minimum and maximum scores, tool purpose and item numbers included in the calculation of scores or sub-scores

Measure	Score/Sub-score	Purpose	Items
Outcome Measures			
Integrated palliative outcome scale (IPOS) [8] family caregiver adapted staff proxy version [46] Lower scores indicate better palliative care outcome in all categories	Total 0-68	Measures palliative care outcomes across physical/psychological symptoms and needs, as well as spiritual/emotional status and practical issues as perceived by family caregiver	1-9; 13-19
	Somatic 0-40	Measures influence of patients' common somatic symptoms on palliative care outcome as perceived by the family caregiver	1-9
	Psychological 0-16	Measures influence of patients' and family caregivers' psychological symptoms on palliative care outcome as perceived by the family caregiver	13-16
	Social 0-12	Measures influence of social factors (e.g. communication, finances) on palliative care outcomes as perceived by family caregiver	17-19
Family carer satisfaction with palliative care scale (FAMCARE-2) [47] Higher scores indicate higher satisfaction with the care provided in SIPC	Total 17-85	Measures overall satisfaction with palliative care provided as perceived by the family caregiver	1-17
	Symptom management and comfort 5-25	Measures influence of symptom management and patients' comfort on family caregiver's satisfaction with care	1,6,7,8,12
	Provision of information 4-20	Measures influence of provision of information about patient's diagnosis and treatment on family caregiver's satisfaction with care	2,3,5,14
	Family support 4-20	Measures influence of support provided by the patient's family on satisfaction with care as perceived by the family caregiver	9,10,11,13
	Patient psychological care 4-20	Measures influence of psychological care provided for the patient on satisfaction with care as perceived by the family caregiver	4,15,16,17
Measures of family caregivers' mental health			
Patient health questionnaire (PHQ-9) [27] Higher scores represent more severe symptoms of depression	0-27	Measures frequency of symptoms of depression in family caregivers over the last two weeks	1-9
Generalised anxiety disorder scale (GAD-7) [29] Higher scores indicate more severe symptoms of anxiety	0-21	Measures frequency of core symptoms of generalised anxiety in family caregivers within the past two weeks	1-7

Integrated Palliative Care Outcome Scale (IPOS)

The Integrated Palliative Outcome Scale (IPOS) is one of the newer scales derived from the Palliative Care Outcome (POS) tool, which was developed in the late 1990s to measure and improve palliative care outcome for a growing population of patients and the family caregivers with terminal illnesses and demand for end-of-life care. It is a 10 item patient reported measure covering the most important issues associated with advanced illness and has since then been used widely in at home, inpatient and hospice settings [6, 22]. To cover specific conditions and symptoms more accurately a symptom module (POS-S) was added, as well as staff versions for both POS and POS-S [33]. Since then both measures have been well tested and shown consistency in various palliative care settings. IPOS combines both POS and POS-S into a single integrated measure. It covers the main domains of concern, including: physical and psychological symptoms, spiritual and practical concerns, emotional burdens and psychological needs of the family and patient [8]. A lower total score on the IPOS indicates better palliative-care outcome [8]. For this study, family caregivers completed an adapted version of the validated 20-item staff questionnaire [46] to allow assessment of their relative’s situation as perceived by the family caregivers.

Items 1-12 ask about the influence of common physical symptoms (e.g. pain, difficulty breathing) during the last week; including nine predefined symptoms, and an additional three free-text options. Items 13-16 measure patient anxiety, as well as family caregivers‘ anxiety. Finally, the last three items focus on communication, information and personal affairs. Items 1-9 are scored from 1-6 using Likert scales (1 = not at all, 2 = a little, 3 = average, 4 = strong, 5 = very strong, 6 = cannot say). Items 13-19 also use Likert scales scored from 1-6, but with alternative score interpretations (1 = not at all, 2 = seldom, 3 = occasionally, 4 = often, 5 = always, 6 = cannot say). Free-text items could capture the patients’ three main problems over the last seven days graded by severity as perceived by the family caregivers scored from 1-6 on a Likert scale (1 = not at all to 5 = always, 6 = cannot say).

We used three standardised sub-scores from the IPOS questionnaire: somatic (items 1-9, scored 0-40), psychological (items 13-16, scored 0-16), and social (items 17-19, scored 0-12). In order to compute scores for further data analysis, the Likert scale was recoded to follow the scoring rules of the IPOS [7]: Any answers scored with six (cannot say) were recoded as missing. In case of missing values, 20% were tolerated for IPOS total score calculation. In situations where missing data for IPSOS responses was greater than 20%, after careful consideration of interpretability and the possibility of subsequent reduced sample size [4] we chose the mean substitution method as most suitable. For the psychological and social sub-scores imputation of missing values was not an option, since these scores only had a small number of calculable items. For these scores individual scores with missing items had to be excluded according to the rules of the IPOS tool.

Family Carer Satisfaction with Palliative Care Scale (FAMCARE-2)

To measure family caregivers' satisfaction with care provided in advanced stages of illness the FAMCARE scale has been widely used since its development in the 1990s. Four main categories have been identified to influence satisfaction with care in a palliative care setting: symptom management and patients' comfort, provision of information about treatment options and clinical management of illness, family support for practical and financial issues, patient psychological care within specialised palliative care. Originally developed to assess at-home palliative care the tool was further adjusted to application in hospice or inpatient palliative care settings. The revised tool is a 17-item questionnaire, the FAMCARE-2 [5]. We used the validated German version of the FAMCARE-2 tool [47].

The FAMCARE-2 questionnaire is interpreted by calculating a total score from 17 to 85. Higher scores indicate higher satisfaction with the palliative care provided. To calculate scores according to the tool's rules the original six-point Likert scale (1 = very satisfied, 2 = satisfied, 3 = undecided, 4 = unsatisfied, 5 = very unsatisfied, 6 = not relevant to my situation) was recoded into a five-point Likert scale. Answers given as six were treated as missing data. We calculated the total score allowing up to 20% of missing values for each individual. Missing values were imputed from the mean score for responses to the relevant questions from all those with a complete response to that question. Four sub-scores were calculated including: 1) symptom management and comfort (Items 1, 6, 7, 8, 12) scored from 5-25; 2) provision of information (Items 2, 3, 5, 14) scored from 4-20; 3) family support (Items 9, 10, 11, 13) scored from 4-20; and 4) patient psychological care (Items 4, 15, 16, 17) scored from 4-20. Higher scores indicated higher satisfaction with the specific area of palliative care.

Depression Screener Patient Health Questionnaire (PHQ-9)

The PHQ-9 (Patient Health Questionnaire) is a 9-item questionnaire that screens for, and assesses severity of, depression in the last two weeks [26]. This tool has been shown to be effective in its assessment and reliable in its use for population comparisons [25].

Items are scored on a four-point Likert scale from 0 = not at all to 3 = nearly every day. Total scores range from 0-27 and higher scores represent more severe symptoms of depression. Total scores of ≥15 indicate severe, 10-14 moderate, 5-9 mild and ≤4 the absence of depression. Normative data for adult persons of the general public in regards to age and sex specific information is available for the German version of this tool used for this study [25].

Generalised Anxiety Disorder Scale (GAD-7)

The GAD-7 is a 7-item tool that assesses generalised anxiety measuring the frequency of the core symptoms within the past two weeks [29, 49].

Items are scored on a four-point Likert scale from 0 = not at all to 3 = nearly every day. The total score ranges from 0-21 and higher scores indicate more severe symptoms of anxiety.

Total scores of ≥15 indicate severe, 10-14 moderate, 5-9 mild and ≤4 the absence of anxiety disorder symptoms.

2.4 Statistical Analyses

We first examined the descriptive characteristics (means, standard deviations, and maximum and minimum values) of participating family caregivers' and patients' characteristics. Attributes considered included general characteristics, such as family caregiver age, sex, relationship to the patient, education.

For both IPOS and FAMCARE-2 responses, we calculated mean (standard deviation [SD]) of the scores for each individual item, total and sub-scores. We conducted a one-way between subjects ANOVA to compare the effect of family caregivers' level of education on palliative care outcome, including Bonferroni method post hoc testing to test the equality of the chosen groups' means. To assess the equality of variances for our chosen variables (caregiver's age, sex, level of anxiety and depression) we performed Levene's test. Levene's test showed that the variances for family caregivers' level of education were not equal. For that reason Mann-Whitney-U testing was used for variables' group comparison.

First we analysed the total IPOS sum scores (scored 0-68), then we investigated responses to the single items in the IPOS questionnaire (items 1-6 and 13-19), before exploring the three sub-scores (somatic, psychological and social). We analysed the responses given in the free-text section and grouped them into 11 sets of symptoms. These were pain, shortness of breath, weakness/fatigue, nausea/vomiting/diarrhoea/constipation, cognitive issues/communication, poor mobility, sadness/depression/worries, fear/restlessness, trouble sleeping, other physical issues (e.g. organ failure, oedema, fever) and other. We were then able to present the number (%) of individuals reporting specific groups of symptoms.

For the FAMCARE-2 firstly total scores (scored 17-85) were analysed, then four sub-scores (symptom management and comfort, provision of information, family support, patient psychological care) were calculated and explored.

Study cohort subgroup division and analyses

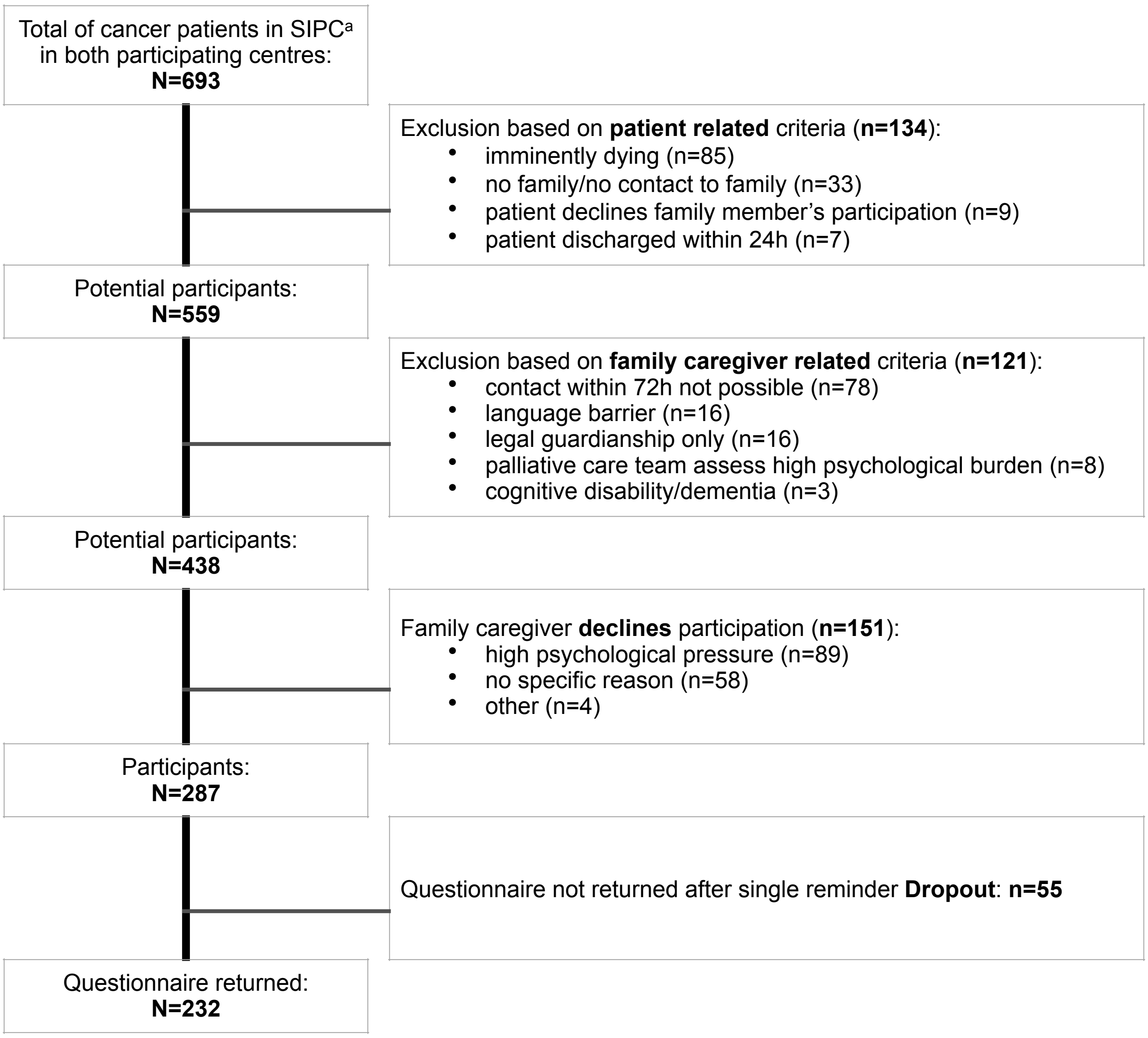
For further analyses the study cohort was divided into subgroups according to family caregivers': age (≤60 or >60), sex, relationship to patient (spouse or other [i.e. parent, child, sibling, other]), education (<9 years; 10 years; 12-13 years), level of anxiety (≤4 to 9 [none to mild] or 10 to ≥15 [moderate to high]) and depression (≤4 to 9 [none to mild] or 10 to ≥15 [moderate to high]), as well as date of first diagnosis of the patients' underlying illness (≤12 months or >12 months). The groups chosen were of sufficient size to support dichotomisation. We tested all variables for normal distribution using the Shapiro-Wilk test (data needs to be normally distributed for t-tests); all variables assessed were not normally distributed, therefore Mann-Whitney-U testing was done for group comparison.

All statistical analyses were carried out using SPSS software version 25.0 (IBM, USA).

3. Results

3.1 Recruitment and sample development

Over a 12-month period dedicated to recruitment we included two hundred and thirty family caregiver-patient units in the study. We initially identified 693 family caregiver-patient units meeting our inclusion criteria (family caregiver ≥18 years, patient with terminal cancer, inpatient, written informed consent). One hundred and thirty four (19%) were excluded due to patient-related criteria (e.g. imminent death, no family or contact to family, declination of family caregiver’s participation, discharge within 24h), 121 (22%) due to family-caregiver-related criteria (e.g. no contact established within 72h of patient admission, language barrier, legal guardianship only, psychological burden too high as assessed by palliative care team, cognitive disability or dementia). Of the 438 potential participants, 151 (35%) declined participation because of high psychological pressure (n=89), or without giving any specific or other reasons (n=58; n=4). The remaining 287 family caregivers received the self-report questionnaire designed for this study. Fifty five (19%) initially included family caregivers did not wish to further participate or failed to return the questionnaire within two working days and after a single reminder. Two hundred and thirty two (81%) participants returned the completed questionnaire and where included in the study population (Figure 1).



[a]SIPC = specialist inpatient palliative care

Figure 1: Recruitment process and sample development

3.2 Study population characteristics

Family caregivers' mean age was 55.5 years (SD 14.8). Almost all family caregivers were German (n=225, 97%) and roughly two thirds were 60 years of age or younger (n=140, 62%) and female (n=150, 66%). Seventy four percent (n=169) of family caregivers were married at the time of completing the questionnaire. The majority of family caregiver and patient units were spouses (n=148, 64%), 26% (n=61) of family caregivers were patients' children, and the remaining participants were either parents (n=5, 2%), siblings (n=7, 3%) or friends (n=11, 5%) of the patient. Two thirds of family caregivers were female (n=150, 66%). Family caregiver's education status was evenly distributed over all three groups defined for this study (≤9 years of school, 10-11 years of school, 12-13 years of school), with a slight majority with 12 years or more in education (n=91, 40%). Over half of all participating family caregivers were working full- or part-time (n=123, 55%), while a third was retired (n=73, 33%). The monthly household income for 43% (n=90) ranged between €2250 and €4000. Thirty-four percent (n=72) had a monthly income lower than €2250 (Table 2).

Table 2: Family caregivers' characteristics (N=232)

Characteristic	**n (%) unless otherwise noted**
Age (years)	
Mean (SD); Range	55.5 (14.8); 20-88
≤60	140 (62.2)
>60	85 (37.8)
Sex	
male	79 (34.5)
female	150 (65.5)
Nationality	
German	225 (97.0)
other	7 (3.0)
Religious affiliation	
yes	153 (67.1)
no	75 (32.9)
Marital status	
single	36 (15.7)
married (living together or separated)	169 (73.8)
widowed/divorced	24 (10.5)
Relationship to patient	
spouse (married/unmarried/separate)	148 (63.8)
parent	61 (26.3)
child	5 (2.2)
sibling	7 (3.0)
other (friend/other)	11 (4.8)
School education	
higher (12-13 years)	91 (39.9)
middle (10-11 years)	72 (31.6)
lower (≤9 years)	65 (28.5)
Employment	
Working (full- or part-time)	123 (55.4)
Retired	73 (32.9)
Not working other than retirement (unemployed, student, apprentice)	26 (11.7)
Monthly Income	
< €2250	72 (34.0)
€2250 to < €4000	90 (42.5)
≥ €4000	50 (23.6)

Abbreviations: % = valid percent; SD = standard deviation

Of the 232 corresponding patients, just over two thirds were 60 years of age or older (n=155, 67%). Fifty-three percent (n=118) were male. More than half had received their diagnosis more than 12 months ago (n=125, 56%) and 45% (n=103) had been cared for at home previous to their admission to the SIPC, while 36% (n=82) had been transferred from another hospital ward to the SIPC unit, and only 14% (n=33) had received specialist outpatient palliative care at home prior to admission. Sixty percent (n=140) of all participating patients had signed an AHCD (Table 3).

Table 3: Patient and care related demographics (N=232)

Characteristic	**n (%)**
Age	
≤60	75 (32.6)
>60	155 (67.4)
Sex	
male	118 (52.9)
female	105 (47.1)
Time since Diagnosis	
>12 months	125 (55.8)
≤12 months	99 (44.2)
Care prior to SIPC	
at home (with/without nursing service)	103 (45.0)
at home with SOPC	33 (14.4)
in hospital	82 (35.8)
nursing home	9 (3.9)
other	2 (0.9)
Patient has AHCD	
yes	140 (60.3)
no	92 (39.7)

Abbreviations: % = valid percent,
SIPC = Specialist Inpatient Palliative Care,
AHCD = Advanced Health Care Directive,
SOPC = Specialist Outpatient Palliative Care

3.3 Palliative Care Outcome

Overall palliative care outcome as measured by IPOS total score

For the IPOS total score, 35 questionnaires (15%) had to be excluded from total score calculation due to missing data exceeding 20% of the relevant items. Ninety questionnaires (39%) were completed by imputing individual mean values for up to 20% of missing data. A comparison of both data sets - no missing data vs. data with imputed values - showed no signs of data corruption after imputation.

The mean IPOS total score reported by family caregivers (as a proxy measure for their ill relatives mental and physical symptoms) was moderate, with 37.9 points (SD 7.7) indicating an overall good palliative care outcome.

Palliative care outcome according to specific subgroups of palliative care as measured by IPOS sub-scores

Forty five questionnaires (19%) had to be excluded for the psychological sub-score and 77 questionnaires (33%) for the social sub-score due to missing data exceeding 20% of the relevant items. In case of the somatic sub-score, 30 questionnaires (13%) had to be excluded. Sixty seven questionnaires (29%) were completed by imputing individual mean values for the missing items. A comparison of both data sets - no missing data vs. data with imputed values - showed no signs of data corruption after imputation.

The somatic and social sub-scores reported by family caregivers were both moderate indicating good palliative care outcome (mean somatic sub-score: 22.2, SD 5.4; mean social sub-score 4.1, SD 2.4) The mean psychological sub-score was highest, suggesting worse palliative care outcome in this domain (mean 11.2, SD 2.9) (Table 4).

Table 4: IPOS total score and sub-scores evaluated by family caregiver during patient's SIPC (N=232)

Total Score	**N**	**Mean (SD)**	**Range**
Score (scored 0-68, with lower scores indicating better palliative care outcome)	197	37.9 (7.7)	12-58

Sub-scores	**N**	**Mean (SD)**	**Range**
Somatic (scored 0-40)	179	22.2 (5.4)	6-36
Psychological (scored 0-16)	187	11.2 (2.9)	2-16
Social (scored 0-12)	155	4.1 (2.4)	0-11

Abbreviations: SD = standard deviation;
SIPC = Specialist Inpatient Palliative Care

Family caregiver reported patient’s experience of most common symptoms

Caregiver anxiety as perceived by the caregivers themselves was rated highest (mean 3.5, SD 0.7). Sixty three percent (n=145) of family caregivers stated that they had always felt anxiety over the last seven days. Of the remainder, almost one third (n=66, 29%) felt anxiety most of the time during that period. Looking at the top three symptoms affecting the patient over the last seven days, as assessed by the family caregivers, weakness/lack of energy (mean 3.4, SD 0.7) and poor mobility (mean 3.4, SD 0.8) scored highest. Weakness/lack of energy was rated as severely (n=98, 44%) or overwhelmingly (n=105, 47%) affecting the patient by almost half of all family caregivers. Over 50% (n=118) of family caregivers rated poor mobility as overwhelmingly affecting the patient. Drowsiness came in second (mean 2.9, SD 1.0), closely followed by pain as the third highest ranking symptom (mean 2.7, SD 1.1). Over two thirds of family caregivers rated pain as affecting the patient severely (n=80, 39%) to overwhelmingly (n=55, 27%). We recorded four areas that most affected individuals in SIPC as observed by their family caregivers with especially low answer return (N<200). These were two symptoms (constipation, dry or sore mouth) and two questions asking for psychological burden (patient is at peace with situation) or flow of information (Table 5).

Table 5: Family caregiver perceived palliative care outcome at beginning of SIPC (N=232)

	N	**Item Mean Value[a]**	**Number (%) with specified response**		
		Mean (SD)	**not at all to moderately[b]** n (%)	**severely** n (%)	**overwhelmingly** n (%)
Pain	207	2.7 (1.1)	72 (34.8)	80 (38.6)	55 (26.6)
Shortness of Breath	208	1.7 (1.4)	138 (66.3)	42 (20.2)	28 (13.5)
Weakness/Lack of Energy	223	3.4 (0.7)	20 (9.0)	98 (43.9)	105 (47.1)
Nausea/Vomiting	207	1.8 (1.4)	125 (60.4)	59 (28.5)	23 (11.1)
Poor Appetite	211	2.6 (1.3)	78 (37.0)	76 (36.0)	57 (27.0)
Constipation	183	1.7 (1.4)	117 (63.9)	42 (23.0)	24 (13.1)
Dry or Sore Mouth	189	2.0 (1.3)	110 (58.2)	51 (27.0)	28 (14.8)
Drowsiness	219	2.9 (1.0)	58 (26.5)	92 (42.0)	69 (31.5)
Poor Mobility	225	3.4 (0.8)	25 (11.1)	82 (36.4)	118 (52.4)
	N	**Mean (SD)**	**not at all to sometimes[c]** n (%)	**most of the time** n (%)	**always** n (%)
Patient Anxiety	210	2.8 (1.0)	75 (35.7)	70 (33.3)	65 (31.0)
Caregiver Anxiety	230	3.5 (0.7)	19 (8.3)	66 (28.7)	145 (63.0)
Patient Sadness/Depression	221	2.7 (0.9)	97 (43.9)	84 (38.0)	40 (18.1)
	N	**Mean (SD)**	**always to sometimes[d]** n (%)	**occasionally** n (%)	**not at all** n (%)
At Peace with Situation	197	2.1 (1.2)	121 (61.4)	44 (22.3)	32 (16.2)
Communication of Emotions	217	1.5 (1.3)	155 (71.4)	45 (20.7)	17 (7.8)
Flow of Information	199	1.1 (1.0)	182 (91.5)	13 (6.5)	4 (2.0)
	N	**Mean (SD)**	**problems addressed to partly addressed[e]** n (%)	**problems hardly addressed** n (%)	**problems not addressed** n (%)
Practical Issues[f]	200	1.7 (1.2)	152 (76.0)	25 (12.5)	23 (11.5)

% = valid percent; SD = standard deviation
[a] lower values indicate better care outcome, range 1-5
[b] not at all, slightly, moderately
[c] not at all, occasionally, sometimes
[d] always, slightly, sometimes
[e] problems addressed, problems mostly addressed, problems partly addressed
[f] e.g. financial

Palliative care outcome subgroup analyses

In subgroup analyses we saw no association between higher IPOS total or sub-scores and family caregivers’ age or sex, and patients’ time since first diagnosis (all p>.1 using Mann-Whitney-U) (Table 6).

Table 6: Group comparisons of IPOS single item scores, total scores and sub scores according to family caregiver's sex, relationship to the patient, age, time since patient's diagnosis of illness, family caregiver's level of anxiety scored with the Generalised Anxiety Disorder Scale (GAD-7) and level of depression scored with the Patient Health Questionnaire (PHQ-9)

IPOS Single Items[a]	N	Family caregiver's age					N	Time since patient's diagnosis				
		≤60		>60		p[b]		>12 months		≤12 months		p[b]
		n	Mean (SD)	n	Mean (SD)			n	Mean (SD)	n	Mean (SD)	
Pain	204	130	2.6 (1.2)	74	2.9 (1.0)	.187	207	131	2.7 (1.2)	76	2.7 (1.0)	.458
Shortness of Breath	205	133	1.7 (1.5)	72	1.7 (1.4)	.803	208	129	1.7 (1.4)	79	1.7 (1.5)	.600
Weakness/Lack of Energy	220	141	3.4 (0.7)	79	3.3 (0.7)	.102	223	137	3.2 (0.8)	86	3.5 (0.6)	.006
Nausea/Vomiting	204	131	1.8 (1.5)	73	1.8 (1.3)	.902	207	129	1.7 (1.4)	78	2.0 (1.5)	.104
Poor Appetite	208	136	2.7 (1.3)	72	2.5 (1.2)	.125	211	134	2.7 (1.3)	77	2.9 (1.2)	.005
Constipation	180	114	1.8 (1.4)	66	1.7 (1.5)	.778	183	121	1.7 (1.4)	62	1.8 (1.5)	.638
Dry or Sore Mouth	187	120	2.0 (1.4)	67	2.1 (1.2)	.424	189	122	1.9 (1.2)	67	2.4 (1.4)	.008
Drowsiness	217	140	2.9 (1.0)	77	2.9 (1.0)	.948	219	135	2.8 (1.0)	84	3.1 (1.0)	.046
Poor Mobility	222	144	3.4 (0.8)	78	3.5 (0.8)	.386	225	140	3.4 (0.8)	85	3.4 (0.7)	.444
Patient Anxiety	207	135	2.8 (1.0)	72	2.9 (1.0)	.663	210	136	2.7 (1.0)	74	3.1 (0.9)	.011
Caregiver Anxiety	227	148	3.5 (0.8)	79	3.6 (0.6)	.770	230	144	3.5 (0.8)	86	3.5 (0.7)	.654
Patient Sadness/Depression	219	143	2.6 (0.9)	76	2.6 (0.9)	.866	221	142	2.5 (0.9)	79	2.9 (0.8)	.012
At Peace with Situation	195	130	2.1 (1.2)	65	2.2 (1.2)	.560	197	124	2.1 (1.3)	73	2.1 (1.1)	.973
Communication of Emotions	215	140	1.6 (1.3)	75	1.5 (1.3)	.507	217	138	1.4 (1.3)	79	1.9 (1.3)	.006
Flow of Information	197	124	1.1 (1.0)	73	1.0 (1.0)	.432	199	128	1.0 (1.0)	71	1.2 (1.0)	.079
Practical Issues[c]	197	130	1.7 (1.2)	67	1.7 (1.2)	.721	200	130	1.7 (1.3)	70	1.7 (1.2)	.950
Scores[a]	**N**	n	Mean (SD)	n	Mean (SD)	p[b]	**N**	n	Mean (SD)	n	Mean (SD)	p[b]
Total Score (0-68)	195	123	37.7 (8.3)	72	38.3 (6.9)	.502	197	126	36.6 (8.2)	71	40.2 (6.3)	.001
Somatic (0-40)	176	110	22.1 (5.6)	66	22.5 (5.2)	.658	179	115	21.8 (5.5)	64	23.0 (5.1)	.169
Psychological (0-16)	185	122	11.1 (3.0)	63	11.4 (2.6)	.583	187	121	11.0 (3.1)	66	11.6 (2.4)	.200
Social (0-12)	154	101	4.1 (2.4)	53	4.1 (2.6)	.830	155	105	3.9 (2.5)	50	4.6 (2.3)	.047

Abbreviations: SD = standard deviation; p = probability of type I error

[a] lower values/scores indicate better care outcome; [b] p-values from Mann-Whitney-U test to calculate the probability that the mean score for IPOS items is different for men and women.

[c] e.g. financial; [d] parent, child, sibling, other

Table 6: Group comparisons of IPOS single item scores, total scores and sub scores according to family caregiver's sex, relationship to the patient, age, time since patient's diagnosis of illness, family caregiver's level of anxiety scored with the Generalised Anxiety Disorder Scale (GAD-7) and level of depression scored with the Patient Health Questionnaire (PHQ-9) - continued

IPOS Single Items[a]	**N**	**Family caregiver's age**					**N**	**Time since patient's diagnosis**				
		≤60		**>60**		p[b]		**>12 months**		**≤12 months**		p[b]
		n	Mean (SD)	n	Mean (SD)			n	Mean (SD)	n	Mean (SD)	
Pain	205	108	2.6 (1.1)	97	2.8 (1.2)	.255	207	126	2.6 (1.2)	81	2.8 (1.1)	.409
Shortness of Breath	205	105	1.6 (1.5)	100	1.8 (1.4)	.183	206	123	1.5 (1.4)	83	2.0 (1.4)	.014
Weakness/Lack of Energy	216	113	3.3 (0.8)	103	3.4 (0.7)	.391	218	132	3.3 (0.7)	86	3.4 (0.7)	.154
Nausea/Vomiting	204	107	1.7 (1.4)	97	1.9 (1.4)	.219	205	127	1.7 (1.4)	78	2.0 (1.4)	.162
Poor Appetite	204	104	2.6 (1.3)	100	2.7 (1.3)	.568	206	126	2.6 (1.3)	80	2.6 (1.2)	.956
Constipation	179	89	1.7 (1.4)	90	1.8 (1.4)	.846	180	108	1.7 (1.5)	72	1.8 (1.4)	.811
Dry or Sore Mouth	185	94	2.2 (1.3)	91	1.9 (1.4)	.210	188	114	2.0 (1.3)	74	2.1 (1.3)	.414
Drowsiness	212	109	3.0 (0.9)	103	2.9 (1.1)	.852	214	129	2.9 (1.0)	85	3.0 (1.0)	.202
Poor Mobility	217	114	3.4 (0.7)	103	3.4 (0.9)	.872	219	134	3.4 (0.7)	85	3.4 (0.9)	.690
Patient Anxiety	202	104	2.6 (1.0)	98	3.0 (1.0)	.005	204	127	2.7 (1.1)	77	3.0 (1.0)	.099
Caregiver Anxiety	222	116	3.3 (0.8)	106	3.8 (0.5)	<.001	224	137	3.4 (0.8)	87	3.7 (0.6)	.001
Patient Sadness/Depression	213	110	2.5 (1.0)	103	2.9 (0.8)	.001	215	132	2.5 (0.9)	83	2.8 (0.9)	.015
At Peace with Situation	192	96	1.8 (1.1)	96	2.4 (1.2)	.002	193	116	2.0 (1.2)	77	2.3 (1.3)	.074
Communication of Emotions	209	106	1.4 (1.2)	103	1.7 (1.4)	.287	211	133	1.6 (1.3)	78	1.5 (1.4)	.754
Flow of Information	192	101	1.0 (0.9)	91	1.2 (1.1)	.307	194	122	1.0 (0.9)	72	1.2 (1.1)	.717
Practical Issues[c]	195	99	1.5 (1.2)	96	1.9 (1.3)	.026	197	123	1.5 (1.2)	74	2.0 (1.2)	.006
Scores[a]	**N**	n	Mean (SD)	n	Mean (SD)	p[b]	**N**	n	Mean (SD)	n	Mean (SD)	p[b]
Total Score (0-68)	193	100	36.4 (7.8)	93	39.6 (7.4)	.002	195	121	36.9 (7.4)	74	39.8 (7.9)	.006
Somatic (0-40)	178	90	21.9 (5.2)	88	22.6 (5.6)	.270	179	106	21.7 (4.9)	73	23.0 (6.0)	.076
Psychological (0-16)	182	92	10.3 (2.9)	90	12.1 (2.5)	<.001	183	113	10.7 (2.9)	70	11.9 (2.8)	.008
Social (0-12)	152	73	3.7 (2.2)	79	4.5 (2.6)	.053	153	96	4.0 (2.3)	57	4.4 (2.6)	.272

Abbreviations: SD = standard deviation; p = probability of type I error
[a]lower values/scores indicate better care outcome; [b]p-values from Mann-Whitney-U test to calculate the probability that the mean score for IPOS items is different for men and women.
[c]e.g. financial; [d]parent, child, sibling, other

Table 6: Group comparisons of IPOS single item scores, total scores and sub scores according to family caregiver's sex, relationship to the patient, age, time since patient's diagnosis of illness, family caregiver's level of anxiety scored with the Generalised Anxiety Disorder Scale (GAD-7) and level of depression scored with the Patient Health Questionnaire (PHQ-9) - continued

IPOS Single Items[a]	**N**	**Family caregiver's age**					**N**	**Time since patient's diagnosis**				
		≤60		**>60**		p[b]		**>12 months**		**≤12 months**		p[b]
		n	Mean (SD)	n	Mean (SD)			n	Mean (SD)	n	Mean (SD)	
Pain	201	129	2.8 (1.1)	72	2.6 (1.2)	.397	202	114	2.6 (1.2)	88	2.8 (1.1)	.377
Shortness of Breath	202	133	1.6 (1.5)	69	1.8 (1.4)	.342	202	111	1.7 (1.4)	91	1.7 (1.4)	.818
Weakness/Lack of Energy	216	139	3.4 (0.8)	77	3.3 (0.7)	.174	218	122	3.2 (0.8)	96	3.5 (0.6)	.026
Nausea/Vomiting	200	131	1.9 (1.4)	69	1.6 (1.3)	.237	203	112	1.8 (1.4)	91	1.8 (1.5)	.670
Poor Appetite	204	128	2.6 (1.3)	76	2.7 (1.1)	.970	205	117	2.5 (1.3)	88	2.8 (1.3)	.049
Constipation	178	115	1.8 (1.5)	63	1.6 (1.4)	.417	180	101	1.7 (1.4)	79	1.9 (1.5)	.448
Dry or Sore Mouth	184	114	2.0 (1.4)	70	2.1 (1.2)	.897	184	102	1.9 (1.3)	82	2.1 (1.3)	.323
Drowsiness	212	136	2.9 (1.0)	76	2.9 (1.0)	.937	213	120	2.9 (1.0)	93	3.0 (1.0)	.432
Poor Mobility	219	138	3.4 (0.8)	81	3.3 (0.8)	.293	218	124	3.3 (0.8)	94	3.5 (0.8)	.097
Patient Anxiety	204	125	2.9 (1.0)	79	2.7 (1.0)	.112	206	118	2.9 (1.0)	88	2.8 (1.0)	.891
Caregiver Anxiety	223	139	3.6 (0.7)	84	3.5 (0.7)	.777	223	124	3.4 (0.7)	99	3.6 (0.8)	.008
Patient Sadness/Depression	215	132	2.7 (0.9)	83	2.5 (0.9)	.094	215	123	2.6 (0.9)	92	2.8 (0.9)	.052
At Peace with Situation	192	125	2.1 (1.2)	67	2.1 (1.2)	.743	191	109	2.1 (1.2)	82	2.1 (1.3)	.973
Communication of Emotions	211	133	1.7 (1.3)	78	1.4 (1.3)	.095	212	118	1.4 (1.2)	94	1.7 (1.4)	.113
Flow of Information	193	123	1.2 (1.0)	70	0.9 (0.9)	.026	194	110	1.1 (1.0)	84	1.1 (1.0)	.803
Practical Issues[c]	194	124	1.7 (1.2)	70	1.7 (1.3)	.850	195	113	1.6 (1.3)	82	1.8 (1.2)	.202
Scores[a]	**N**	n	Mean (SD)	n	Mean (SD)	p[b]	**N**	n	Mean (SD)	n	Mean (SD)	p[b]
Total Score (0-68)	191	124	38.5 (7.7)	67	37.0 (7.9)	.124	193	111	36.9 (8.0)	82	39.5 (7.1)	.066
Somatic (0-40)	174	118	22.4 (5.6)	56	22.0 (5.1)	.372	176	98	21.6 (5.5)	78	23.1 (5.2)	.267
Psychological (0-16)	182	117	11.3 (2.9)	65	11.0 (2.9)	.301	184	106	11.0 (2.9)	78	11.5 (2.8)	.220
Social (0-12)	151	100	4.3 (2.5)	51	3.8 (2.3)	.263	151	86	3.9 (2.4)	65	4.5 (2.5)	.168

Abbreviations: SD = standard deviation; p = probability of type I error

[a] lower values/scores indicate better care outcome; [b] p-values from Mann-Whitney-U test to calculate the probability that the mean score for IPOS items is different between both groups

[c] e.g. financial; [d] parent, child, sibling, other

Family caregiver anxiety and depression

The most notable differences were found in regards to objectively measured family caregivers' levels of anxiety and depression, as opposed to self-reported family caregiver anxiety and depression. We measured actual family caregiver anxiety using the Generalised Anxiety Disorder Scale (GAD-7) and family caregiver depression using the Patient Health Questionnaire (PHQ-9). Family caregivers with moderate-to-high anxiety levels (47%, n=106) showed strong evidence of associations to higher scores for patient anxiety (p=.005), caregiver anxiety (p<.001), patient sadness/depression (p=.001) and whether the patient was at peace with the situation (p=.002). There was less evidence (p=.26) for higher single item scores being associated with practical issues (e.g. finances). There was strong evidence to suggest that higher total IPOS scores (mean 39.6, SD 7.4; p=.002) and psychological scores (mean 12.1, SD 5.6; p<.001) were also associated with moderate to high anxiety levels in family caregivers. Family caregivers with moderate to high levels of depression (39%, n=87) scored significantly higher single items values in regards to patient shortness of breath (p=.014), caregiver anxiety (p=.001), patient sadness/depression (p=.015) and practical issues (p=.006). There was also strong evidence that moderate-to-high caregiver depression levels was related to higher total (mean 39.8, SD 7.9; p=.006) and psychological sub-scores (mean 11.9, SD 2.8; p=.008).

Family caregiver relationship to patient

Non-spouse family caregivers scored higher total IPOS scores showing a strong association with worse care outcome (mean 40.2, SD 6.3; p=.001) as well as higher social sub-scores (p=.047). Additionally non-spouse family caregivers also reported higher single items values for proxy-assessed weakness/lack of energy (p=.006), poor appetite (p=.005), dry or sore mouth (p=.008) and communication of emotion (p=.006) in comparison to patients' spouses. Weaker evidence of associations were found between being a none-spouse family caregiver and patient's affection by drowsiness (p=.046), patient anxiety (p=.011) and patient sadness/ depression (p=.012).

Family caregiver characteristics

Lower family caregivers' age showed moderate evidence of an association (p=.026) to higher single item values regarding flow of information. Family caregivers' lower to mid-range education showed moderate evidence of an association (p=.036) with higher psychological sub-scores. Higher education of family caregivers corresponded with higher single item values for patient constipation at a strong level (p=.002) and a moderate level (p=.018) for communication of emotions.

Time since diagnosis

Family caregivers of patients who were first diagnosed fewer than 12 months prior to SIPC had strong evidence of higher (p=.008) single item scores in regards to caregiver anxiety.

Additionally moderate evidence of an association to higher single item values for weakness/ lack of energy (p=.026) and poor appetite (p=.049) were reported.

Main clinical problems as perceived by family caregivers

Family caregiver perceived patients' pain was given as one of the three main problems in the majority of cases. Almost a third (n=62, 31%) of family caregivers felt it was the most severe problem, followed by patient's shortness of breath (n=25, 12%) and weakness/fatigue (n=22, 11%) and other physical issues (i.e. organ failure, oedema, fever) (n=22,11%). Pain and other physical issues were equally measured as the second most severe problem during the last week at 18% (n=30), followed closely by nausea/vomiting/diarrhoea/constipation (n=28, 17%) and weakness/fatigue (n=27, 16%). Even when asked for the third main issue of the past week pain still ranged in the top three symptoms at 14% (n=17). In this category weakness/fatigue and nausea/vomiting/diarrhoea/constipation ranged most important with 17% (n=20) (Table 7).

Table 7: Problems of patient as perceived by family caregiver over the last seven days during patient's SIPC (N=232)

Problems over last seven days	**Most severe problem n (%)**	**Second most severe problem n (%)**	**Third most severe problem n (%)**
	N=201	**N=176**	**N=120**
Pain	62 (30.8)	30 (18.0)	17 (14.2)
Shortness of Breath (SOB)	25 (12.4)	5 (3.0)	5 (4.2)
Weakness/Fatigue	22 (10.9)	27 (16.2)	20 (16.7)
Other Physical Issues (i.e. organ failure, oedema, fever)	22 (10.9)	30 (18.0)	15 (12.5)
Nausea/Vomiting/ Diarrhoea/Constipation	21 (10.4)	28 (16.8)	20 (16.7)
Cognitive Issues/Communication	17 (8.5)	11 (6.6)	6 (5.0)
Poor Mobility	11 (5.5)	9 (5.4)	8 (6.7)
Other	8 (4.0)	8 (4.8)	8 (6.7)
Sadness/Depression/Worries	6 (3.0)	10 (6.0)	15 (12.5)
Fear/Restlessness	5 (2.5)	8 (4.8)	<5 (3.3)
Trouble Sleeping	<5 (1.0)	<5 (0.6)	<5 (1.7)

Abbreviations: % = valid percent
SIPC = Specialist Inpatient Palliative Care

3.4 Family caregivers’ satisfaction with specialist inpatient palliative care

Family caregivers’ satisfaction with care as measured by FAMCARE-2 total sum scores

Overall ratings of the FAMCARE-2 total sum score were high (mean 73.7 [out of 85] SD 9.6) with no score lower than 44, indicating high satisfaction with care in the study cohort.

Family caregivers’ satisfaction with care according to specified subgroups of care as measured by FAMCARE-2 sub-scores

Similarly, high scores were recorded in all four sub-scores (Table 8).

Table 8: FAMCARE-2 total score and sub-scores evaluated by family caregiver during patient’s SIPC (N=232)

Total sum score	**N**	**M (SD)**	**Range**
Score 17-85	197	73.7 (9.6)	44-85
Sub-scores	**N**	**M (SD)**	**Range**
Symptom Management and Comfort (5-25)	199	22.3 (3.0)	12-25
Provision of Information (4-20)	165	16.5 (3.0)	7-20
Family Support (4-20)	158	17.0 (2.8)	8-20
Patient Psychological Care (4-20)	194	17.9 (2.3)	10-20

M = mean; SD = standard deviation
SIPC = Specialist Inpatient Palliative Care

Family caregivers’ satisfaction with care according to specific areas of care as measured by FAMCARE-2 single item scores

All items evaluated showed high levels of satisfaction with over 80% of included family caregivers being satisfied or very satisfied at the beginning of SIPC. Only three single items scored lower than 80%: information given about side effects of treatment (n=137, 71%), meetings with PCT to discuss patient’s condition and plan of care (n=144, 77%), emotional support provided to family members by PCT (n=151, 78%).

A detailed table of the single item responses to the FAMCARE-2 is included in the appendix.

Satisfaction with care subgroup analyses

We found no association between higher satisfaction with care overall or higher FAMCARE-2 sub-scores in regards to family caregivers’ sex or levels of depression or anxiety. (Table 9)

Table 9: Group comparisons of FAMCARE-2 total scores and sub scores showing satisfaction with overall care and specific areas of care according to family caregiver's sex, age, family caregiver's level of anxiety scored with the Generalised Anxiety Disorder Scale (GAD-7) and level of depression scored with the Patient Health Questionnaire (PHQ-9) (N=232)

Total score[a]	**Complete study cohort**			**Family caregiver's sex**						**Family caregiver's age**					
				N	**female**		**male**		p[b]	**N**	**≤60**		**>60**		p[b]
	n	Mean (SD)	Range		n	Mean (SD)	n	Mean (SD)			n	Mean (SD)	n	Mean (SD)	
Score 17-85	197	73.7 (9.6)	44-85	195	124	73.7 (9.5)	71	73.5 (9.9)	.984	190	124	72.9 (10.1)	66	75.0 (8.7)	.272
Sub scores	n	Mean (SD)	Range	**N**	n	Mean (SD)	n	Mean (SD)	p[b]	N	n	Mean (SD)	n	Mean (SD)	p[b]
Symptom Management and Comfort (5-25)	199	22.3 (3.0)	12-25	197	129	22.3 (2.9)	68	22.4 (2.9)	.556	192	128	22.1 (3.1)	64	22.7 (2.5)	.351
Provision of Information (4-20)	165	16.5 (3.0)	7-20	163	97	16.5 (3.1)	66	16.5 (3.0)	.819	158	106	16.2 (3.2)	52	17.2 (2.7)	.077
Family Support (4-20)	158	17.0 (2.8)	8-20	156	97	17.0 (2.7)	59	16.9 (2.9)	.886	152	102	16.8 (2.9)	50	17.4 (2.6)	.322
Patient Psychological Care (4-20)	194	17.9 (2.3)	10-20	192	123	17.9 (2.2)	69	17.7 (2.5)	.842	188	120	17.7 (2.5)	68	18.1 (2.0)	.374

Abbreviations: M = mean; SD = standard deviation; z = statistical significance ; p = probability of type I error
[a] higher scores indicate higher satisfaction with care
[b] p-values from Mann-Whitney-U test to calculate the probability that the mean score for FAMCARE-2 scores is different between both groups

Table 9: continued

Total score[a]	**Family caregiver's depression**						**Family caregiver's anxiety**					
	N	**none to mild**		**moderate to high**		p[b]	**N**	**none to mild**		**moderate to high**		p[b]
		n	Mean (SD)	n	Mean (SD)			n	Mean (SD)	n	Mean (SD)	
Score 17-85	193	117	73.5 (9.9)	76	73.7 (9.2)	1.000	192	104	73.0 (10.4)	88	74.3 (8.7)	.561
Sub scores	**N**	n	Mean (SD)	n	Mean (SD)	p[b]	N	n	Mean (SD)	n	Mean (SD)	p[b]
Symptom Management and Comfort (5-25)	195	114	22.4 (3.0)	81	22.2 (2.9)	.403	194	100	22.2 (3.2)	94	22.4 (2.6)	.912
Provision of Information (4-20)	163	100	16.4 (3.1)	63	16.7 (2.9)	.610	161	92	16.4 (3.1)	69	16.7 (2.9)	.483
Family Support (4-20)	156	95	17.0 (2.9)	61	16.9 (2.6)	.584	155	84	16.7 (3.0)	71	17.4 (2.5)	.227
Patient Psychological Care (4-20)	191	118	17.8 (2.4)	73	17.9 (2.2)	.927	189	102	17.7 (2.5)	87	18.0 (2.1)	.841

Abbreviations: M = mean; SD = standard deviation; z = statistical significance ; p = probability of type I error
[a] higher scores indicate higher satisfaction with care
[b] p-values from Mann-Whitney-U test to calculate the probability that the mean score for FAMCARE-2 scores is different between both groups

4. Discussion

We aimed to explore the factors influencing family caregivers' satisfaction with care and self-reported palliative care outcome as perceived by family caregivers in a specialist inpatient care setting and identify possible improvements in clinical data analyses. In our study cohort, we could not identify specific characteristics to predict higher or lower satisfaction with care nor better or worse palliative care outcome. A large majority showed scores that equal high levels of satisfaction with care and good palliative care outcome, suggesting that within even the first seven days of admission to hospital patient and family caregivers' needs are met by the care provided in SIPC.

4.1 Satisfaction with care as perceived by family caregivers

Satisfaction with services offered by health care providers has been identified as an important marker to measure successful quality of care in all areas of health care. After recent studies assessing the importance of satisfaction with specialised palliative care within the collective of out- and inpatient specialised palliative care patients [16, 31] satisfaction with care has been included as a feature of successful palliative care. Family caregivers' perception of care can influence how burdens and bereavement are processed [50]. Studies examining satisfaction with palliative care have shown high satisfaction in all settings of palliative care (at home, hospice, outpatient or inpatient specialised palliative care) over all [5, 32, 51]. Contrary to a previous study by Fakhoury et al. (1996) identifying age and level of education as associated factors of family caregivers' satisfaction with care, we could not show strong evidence for differences in family caregivers' satisfaction with care for these variables.

Communication and flow of information during SIPC and satisfaction with care

The lowest subgroup scores were reported in family caregivers' satisfaction with information provided about their family member and the planned course of palliative care. The biggest difference in our subgroup analyses could be shown in the satisfaction with flow of information in family caregivers over 60 years old (M 16.2; SD 3.2) and those younger than 60 years old (M 17.2; 2.7). Though of moderate statistical relevance ($p=.07$) our results help underline the importance of good communication and flow of information for family caregivers' satisfaction with care in palliative care settings [16, 21, 31]. However, studies considering intensified flow of information could not show improvement in family caregiver anxiety or depression [30], two of the main burdens identified for family members caring for patient with life limiting advanced disease [27, 35, 36, 39, 40].

Positive skew of satisfaction with care

All scores and sub-scores of the FAMCARE-2 measuring family caregivers' satisfaction with care in our study collective were positively skewed. This phenomenon has been shown in previous studies [5, 17, 32, 51], and we expected this result. The positive skew could be due to family caregivers needs being met by palliative care even within first initialisation of specialised palliative care, be it at home or in outpatient or inpatient settings. However, the phenomenon could also be a reflection of the carers reluctance to issue complaints or ask for more assistance in a highly dependant situation [5, 16, 28, 44, 50]. When changes in satisfaction with care were measured over time improvements in satisfaction were associated with availability of care, flow of information from health care providers to family caregivers and successful symptom control [16, 31, 43]. No larger differences between total and sub-scores over all domains could be identified in this study. Satisfaction with care was high at the beginning of specialist palliative care over all domains (symptom management, provisions of information, family support, patient psychological care) and further analysed and compared subgroups (family caregiver age, sex, levels of anxiety and depression). Eighty percent of all participants reported to be satisfied or very satisfied with the care provided at the beginning of SIPC within the first seven days of admission.

4.2 Family caregiver reported palliative care outcome

Family caregiver reported palliative care outcome was scored slightly higher translating into worse palliative care outcome in comparison to other studies collecting patient or staff reported palliative care outcome using applicable versions of IPOS or POS questionnaires [8, 34]. Data collected in those studies was taken during the first two to five days of specialised palliative care. Compared to the pilot study for this project using the POS questionnaire for family caregivers, overall outcome was similarly scored without any group differences [51]. This suggests family caregiver evaluations of their family members palliative care outcome is worse than patient's own assessment of their situation and has to be considered when evaluating palliative care outcome through the lens of the family caregiver. Another study conducted recently at the at the University Medical Center of Hamburg, Germany, one of the centres included in this study, by Coym et al. (2020) showed lower IPOS scores closer to scores reported by other studies using data directly collected from the patients themselves. However, in 44% of the included IPOS scores the patient was at least helped by the family caregiver to answer the questionnaire [14]. Whether there was any evidence of higher IPOS scores in this group was not reported.

Family caregiver anxiety and depression and palliative care outcome

Family caregivers of terminally ill patients face social isolation and a higher risk of developing anxiety or symptoms of depression compared to the general public [18]. While we could not identify specific family caregivers' characteristics (age, sex or level of education) to have an impact on higher satisfaction with care, IPOS total scores as well as the psychological sub-scores of family caregivers with moderate to high levels of anxiety and depression were strongly associated with lower IPOS scores and therefore worse palliative care outcome. Two thirds of all family caregivers in this study reported higher levels of self-assessed anxiety every day during the last seven days within the IPOS questionnaire. A study by Lambert et al. (2013) also shows an association between higher levels of family caregiver anxiety and depression and worse palliative care outcome when assessed by family caregivers [27]. Family caregivers with moderate to high anxiety levels scored higher IPOS single item scores regarding family caregiver perceived patient anxiety as well as self assessed anxiety during the last seven days. Additionally these family caregivers also perceived the patient to be less at peace with the situation.

Family caregiver relationship to patient and palliative care outcome

Out of all family caregiver characteristics included in our study only the relationship to the patient (spouse or other) showed strong connection to worse overall palliative care outcome in those family caregivers who were not the patients' spouse. These family caregivers specifically scored higher in regards to family caregiver perceived patient symptoms (weakness or lack of energy, poor appetite, dry or sore mouth) with strong evidence in connection to worse care outcome scores. Weakness or lack of energy was also recorded as one of the most concerning patient symptom over the last seven days as perceived by family caregivers in our free text question on the adapted IPOS questionnaire used in this study. Well over two thirds of family members who were not the spouse of the patient were the patient's child. Assuming that spousal communication is more direct than that between parents and their adult children in advanced illness settings, the relationship characteristics of non-spousal family caregivers could be one explanation for differences in worse palliative outcome care for this group.

4.3 Implications for research and clinical practice

Identifying at risk family caregivers offers the potential to increase their positive impact on holistic palliative care. Hudson et al. (2011) identified key areas of positive impact on palliative care provided by family caregivers. They include improvement of patient palliative care outcome, the potential to gain positive outcomes in the role as informal primary caregiver, achieving and improving the quality of home care and help reduce the costs of successful palliative care [23]. While we could not find many characteristics of family caregivers in special need of support when analysing palliative care outcome and satisfaction with care as perceived by the family caregiver, there is room for improvement in the communication and family caregiver anxiety domains.

Improvement of communication and flow of information

The inclusion of communication and flow of information as a marker for quality of care and care outcome already proves that this area plays an important role in meeting family caregivers needs in a palliative care setting. Communication can be twofold: it includes communication between family caregivers and care providers as well as communication between family caregivers and their family member admitted to palliative care. In an integrative review by Robinson et al. (2014) family caregivers often criticised the lack of information about the treatment plan for their family member. Though this study included all setting for palliative care and not only specialised palliative care wards, it underlines our findings of good flow of information being connected to higher family caregiver satisfaction with care [44]. Good communication between staff and family caregivers also enables family caregivers to effectively participate in end-of-life care decision making and can positively impact family caregivers' experience.

Areas of ambivalence in palliative care outcome evaluation of family caregivers

Our data revealed that certain questions were less often responded to than others. We recorded especially low feedback on IPOS single items regarding some patient symptoms (constipation, dry or sore mouth), psychological aspects (patient is at peace with situation) and family caregivers' view on the flow of information. These areas have been identified as especially difficult to answer in previous studies and might be a sign of family caregivers struggling to properly evaluate the patient's symptoms in some areas and reluctance to criticise the quality of care while feeling reliant on the team providing palliative care [32, 52]. Assessment of satisfaction with care over a longer period of time would allow a more conclusive interpretation of data collected. The FAMCARE-2 could be handed out to patients and their family caregivers at different points in time during their stay in hospital and show any changes in satisfaction with care connected to, for example, interventions offered to address family caregiver anxiety or depression and patients' symptom burden.

Evaluation of family caregivers' satisfaction with care and palliative care outcome over time

This study used data from only one point of time and can therefore not make any report on changes of family caregivers' levels of satisfaction and outcome of care over time spent in SIPC. Evaluation of satisfaction with care and palliative care outcome over time open opportunities to identify at risk family caregiver and inpatient dyads and provide them with the necessary interventions. The IPOS score especially is a good and easily applied tool to evaluate patient and family caregiver needs throughout a stay in hospital. In a presentation on outcome research Bausewein (2016) proposed a heat map using the total score as well as single item values to follow patients' development of symptoms and needs over time [7]. With patient in SIPC who are no longer able to complete their own questionnaires, proxy evaluation through their family caregiver is also feasible. The application of the IPOS tool in this way, would allow to regularly assess outcome of care. With proxy evaluations' improvement over time [32] regular assessment at different points of SIPC is key to ensure the quality and accuracy of information provided. An assessment of total scores as well as symptom burden separately allows to address the most problematic areas if and when needed and may further improve care outcome. Including the family caregivers in care decision making and respecting their evaluations on the situation could be another way to enable family caregivers to have a positive experience in a difficult situation and has the potential to improve family caregivers overall outcome [23].

4.4 Strengths

This study reflects data from a two-site study from an inpatient specialist palliative care setting with similar service provision models. Both sites represent different living environments. As such, these findings represent a specific set of circumstances often found in German oncological specialist palliative care. As a consecutive cohort for the questionnaire was sought from both participating sites, selection bias has been minimised. The study cohort shows a balance between sexes, ages and other sociodemographic factors. Therefore, simple two-sided group comparisons were performed without overrepresentation of one group over the other. To minimise recall bias, the questionnaire was handed out while participating family caregiver-patient units were receiving inpatient specialist palliative care. Thus reducing the significant changes in reported data when collecting retrospectively [5, 44].

4.5 Limitations

Given the pronounced positive skew of the data collected with all participants of this study scoring highly for satisfaction with care and palliative care outcome, detecting changes or improvement of satisfaction with care and palliative care outcome can be limited. This phenomenon has been previously described in other studies [17, 32]. Palliative care units do not only provide for people with an underlying lifetime limiting oncological illness, but other non-oncological terminal illnesses too. However, to ensure comparability and stability of the data collected, we opted for the largest possible sample size and focused recruitment on inpatients with a terminal oncological illness. Missing data is always a challenge in statistical analyses. Before applying mean value substitution for missing values for data analyses of IPOS and FAMCARE-2 scores, we compared participants with missing data and without missing data and found no evidence for differences in both groups. This ensured the validity of the imputed data.

5. Conclusion

Overall, satisfaction with care was high. Likewise, the palliative care outcome was good for family caregivers in our study cohort. Family caregivers with worse palliative care outcome showed higher levels of anxiety and depression. While we could not find evidence for differences in satisfaction with care and palliative care outcome connected to demographic characteristics of family caregivers, flow of information, good communication and treating family caregiver anxiety could improve palliative care outcome. Our study reinforces the call for more coherent data in palliative care and the development of problem-focussed interventions to improve specific aspects of the care provided to patients as well as their family caregivers. The holistic approach to palliative care provides care for family caregivers and their ill family member, but still has room for improvement. Correct implication of available tools to assess palliative care in its various settings (at home with or without specialised care providers, outpatient clinics, inpatient settings) is crucial to understanding and identifying family caregivers and patients in need of extra support during specialised palliative care. Therefore, further research has to be done examining changes in family caregivers' levels of anxiety and depression over time as well as before, during and after intervention. Raising awareness about family caregivers needs and building on the available services will improve palliative care further. In conclusion, we were able to show that specialist palliative care provides patients and their family caregivers with much needed support and can improve care outcome.

6. Abbreviations

EAPC - European Association for Palliative Care
FC - Family Caregiver
IPOS - Integrated Palliative Care Outcome Scale
SIPC - Specialist Inpatient Palliative Care
SOPC - Specialist Outpatient Palliative Care
AHCD - Advanced Health Care Directive

7. Abstract

Background: This thesis focuses on family caregivers‘ satisfaction with care and palliative care outcome at the beginning of specialised inpatient palliative care as part of a project aiming to examine psychosocial burdens, need for assistance and satisfaction with assistance offered to caregivers of people in an inpatient palliative care setting with a terminal oncological illness during and after palliative care. It aims to examine whether there are specific influences on family caregivers‘ satisfaction with care and palliative care outcome.

Methods: Within 72 hours after patient admission to the specialised palliative care unit we asked family caregivers to complete German versions of the family carer satisfaction with palliative care scale (FAMCARE-2) and adapted staff version of the integrated palliative outcome scale (IPOS) to assess satisfaction with care and palliative care outcome at the beginning of SIPC. To evaluate family caregivers’ mental health we also asked them to complete the generalized anxiety disorder 7-item scale (GAD-7), patient health questionnaire depression module 9-item scale (PHQ-9).

Results: In 232 family caregivers satisfaction with care was high (mean 73.7; SD 9.6) with no specific identifiable characteristics connected to higher or lower levels of satisfaction with care. Palliative care outcome had a mean total score of 37.9 points (SD 7.7) indicating an overall good palliative care outcome. Non-spouse family caregivers scored higher total IPOS scores (mean 40.2, SD 6.3; p=.001) associated with worse care outcome. Higher total IPOS (mean 39.6, SD 7.4; p=.002) and psychological sub scores (mean 12.1, SD 5.6; p<.001) were also associated with moderate to high anxiety levels in family caregivers.

Conclusion: Family caregivers with relatives in specialised inpatient palliative care are satisfied with the care provided. Palliative care outcome can be improved by focussing on family caregivers’ psychological needs.

Zusammenfassung

Hintergrund: Diese Dissertation untersucht die Betreuungszufriedenheit und -qualität spezialisierter stationärer Palliativversorgung eingeschätzt durch Angehörige. Sie ist Teil eines Studienprojekts, welches die psychosozialen Belastungen, Unterstützungsbedürfnisse und die Betreuungszufriedenheit von pflegenden Angehörigen terminal onkologisch erkrankter Patienten auf einer spezialisierten Palliativstation untersucht. Ziel ist spezifische Einflussfaktoren auf die Betreuungszufriedenheit und -qualität zu identifizieren und untersuchen.

Methoden: Angehörige wurden innerhalb von 72 Stunden nach Aufnahme auf die Palliativstation gebeten deutsche Versionen der Family carer satisfaction with palliative care scale (FAMCARE-2) und adaptierten Fassung der Integrated palliative outcome scale (IPOS) zu beantworten, um die Betreuungszufriedenheit und Qualität der Versorgung am Anfang der spezialisierten stationären Palliativversorgung zu erfassen. Angst und Depression der Angehörigen wurde mit der Generalized anxiety disorder 7-item scale (GAD-7) bzw. der Patient health questionnaire depression module 9-item scale (PHQ-9) evaluiert.

Ergebnisse: In der Auswertung von 232 Fragebögen teilnehmender Angehöriger zeigte sich eine hohe Betreuungszufriedenheit (M 73.7; SD 9.6) ohne spezifische Faktoren in Verbindung mit höherer oder niedriger Zufriedenheit. Die Qualität der Betreuung wurde im Mittel ebenfalls als gut bewertet (M 37.9; SD 7.7). Angehörige die nicht Partner des Patienten waren, zeigten höhere Werte in der allgemeinen IPOS-Skala (M 40.2, SD 6.3; p=.001) und somit eine schlechtere Betreuungsqualität. Höhere Werte in den allgemeinen IPOS-Skalen (M 39.6, SD 7.4; p=.002), sowie der Subskala zur Bewertung psychologischer Einflüsse (M 12.1, SD 5.6; p<.001) waren assoziiert mit stärker ausgeprägten Ängsten der Angehörigen.

Schlussfolgerung: Angehörige mit Familienmitgliedern in spezialisierter stationärer Palliativversorgung sind zufrieden mit dem bestehenden Betreuungsangebot. Die Qualität der Betreuung kann durch gezielte Verbesserung der psychologischen Bedürfnisse der Angehörigen noch gesteigert werden.

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9. Acknowledgements

I want to thank my supervisors Prof. Karin Oechsle, MD, Anneke Ullrich, MS, for their advice and help with this project. I want to express my heartfelt appreciation to all family caregivers for their effort in participating in this study while caring for a terminally ill patient. Special gratitude also to my family and dear friends, Georgia Tran, Hannah Vogeler and Kate Mansfield for holding my hand through this process.

10. CV

Redacted from the public record due to privacy rules.

11. Declaration of Academic Honesty

Ich versichere ausdrücklich, dass ich die Arbeit selbständig und ohne fremde Hilfe verfasst, andere als die von mir angegebenen Quellen und Hilfsmittel nicht benutzt und die aus den benutzten Werken wörtlich oder inhaltlich entnommenen Stellen einzeln nach Ausgabe (Auflage und Jahr des Erscheinens), Band und Seite des benutzten Werkes kenntlich gemacht habe.
Ferner versichere ich, dass ich die Dissertation bisher nicht einem Fachvertreter an einer anderen Hochschule zur Überprüfung vorgelegt oder mich anderweitig um Zulassung zur Promotion beworben habe.
Ich erkläre mich einverstanden, dass meine Dissertation vom Dekanat der Medizinischen Fakultät mit einer gängigen Software zur Erkennung von Plagiaten überprüft werden kann.

Unterschrift: ....

12. Appendix

Appendix Table 1: Family caregivers evaluation of satisfaction with palliative care provided at the beginning of SIPC

FAMCARE-2 Single Items	**N**	**Mean (SD)**	**very dissatisfied** n (%)	**dissatisfied** n (%)	**undecided** n (%)	**satisfied** n (%)	**very satisfied** n (%)
Patient’s comfort	222	4.6 (0.6)	0 (0.0)	1 (0.5)	12 (5.4)	67 (30.2)	142 (64.0)
Way in which patient’s condition and likely progress have been explained by PCT	210	4.2 (0.8)	0 (0.0)	8 (3.8)	28 (13.3)	84 (40.0)	90 (42.9)
Information given about side effects of treatment	194	3.9 (1.0)	3 (1.5)	13 (6.7)	41 (21.1)	78 (40.2)	59 (30.4)
Way in which PCT respects patient’s dignity	221	4.7 (0.6)	1 (0.5)	0 (0.0)	7 (3.2)	42 (19.0)	171 (77.4)
Meetings with PCT to discuss patient’s condition and plan of care	188	4.1 (0.9)	1 (0.5)	7 (3.7)	36 (19.1)	64 (34.0)	80 (42.6)
Speed with which symptoms are treated	209	4.3 (0.8)	1 (0.5)	6 (2.9)	24 (11.5)	81 (38.8)	97 (46.4)
PCT’s attention to patient’s description of symptoms	217	4.5 (0.8)	0 (0.0)	6 (2.8)	18 (8.3)	63 (29.0)	130 (59.9)
Way in which patient’s physical needs for comfort are met	221	4.6 (0.7)	0 (0.0)	3 (1.4)	14 (6.3)	50 (22.6)	154 (69.7)
Availability of PCT to family	214	4.3 (0.8)	2 (0.9)	3 (1.4)	27 (12.6)	70 (32.7)	112 (52.3)
Emotional support provided to family members by PCT	194	4.1 (0.9)	1 (0.5)	7 (3.6)	35 (18.0)	76 (39.2)	75 (38.7)
Practical assistance provided by PCT	170	4.3 (0.8)	1 (0.6)	1 (0.6)	26 (15.3)	57 (33.5)	85 (50.0)
Doctor’s attention to patient’s symptoms	212	4.4 (0.8)	0 (0.0)	5 (2.4)	24 (11.3)	73 (34.4)	110 (51.9)
Way family is included in treatment and care decisions	203	4.2 (0.9)	1 (0.5)	9 (4.4)	31 (15.3)	76 (37.4)	86 (42.4)
Information given about how to manage patient’s symptoms	209	4.2 (0.9)	1 (0.5)	9 (4.3)	24 (11.5)	86 (41.1)	89 (42.6)
How affectively PCT manages patient’s symptoms	210	4.3 (0.8)	0 (0.0)	3 (1.4)	27 (12.9)	80 (38.1)	100 (47.6)
PCT’s response to changes in patient’s care needs	213	4.4 (0.7)	0 (0.0)	1 (0.5)	24 (11.3)	69 (32.4)	119 (55.9)
Emotional support provided to patient by PCT	207	4.3 (0.8)	0 (0.0)	4 (1.9)	36 (17.4)	67 (32.4)	100 (48.3)

Abbreviations: % = valid percent; M = mean; SD = standard deviation; PCT = palliative care team, SPIC = specialised inpatient palliative care