

ORIGINAL PAPER

FAMILY CAREGIVER SATISFACTION WITH HOME-BASED PALLIATIVE CARE SERVICES IN NORTH RHINE-WESTPHALIA, GERMANY

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Abstract

Aim: The aim of this study was to give an overview of family caregiver satisfaction within the home palliative care situation in North Rhine-Westphalia, Germany. **Design:** A cross-sectional study. **Methods:** An anonymous questionnaire, with seven validated scales, and comprising of 71 items, was used. The items investigated perceived needs and burdens of families within a home-based palliative care situation. The satisfaction of the family caregivers with the services delivered by palliative care teams was measured by the FAMCARE-2 Scale. Descriptive statistics and analysis of covariance (ANCOVA) were performed. **Results:** A convenience sample of 106 family members agreed to participate in the study. Overall, we found high satisfaction within our sample. There was high satisfaction with how the services respected the dignity of families, and how they provided comfort to patients. Satisfaction was lower with regard to information about patients. **Conclusion:** High or low satisfaction with palliative care, tells us little about the quality of services. The high satisfaction within this study could be interpreted as a sign that palliative care was important to families at the time of availability. Regular and continuous assessment can serve to inform the continuous quality of care provision for patients and their families.

Keywords: family, home, palliative care, quantitative research, satisfaction of care.

Introduction

Palliative home care aims at the preservation and improvement of both patients and their families' quality of life at the end of life, including the time after bereavement (World Health Organisation, 2002). Indeed, patients and their families have several needs in common, but differences between them should also be addressed (Longman et al., 1992). To achieve this aim, it is necessary to have adequate and systematic information on the perceived needs and burdens of families within a palliative care situation. This is particularly true of families in home-based palliative care settings; who face imminent loss, and may experience complicated bereavement. At the same time, they are also involved in patient care, which often comes with

numerous stressors and burdens (Ringdal, Jordhøy, Kaasa, 2003; Hudson et al., 2011). Due to their unique social and disease-related situation, family members have special individual needs and burdens (Longman et al., 1992), which are associated with negative physical, psychosocial and social impacts (Rossi Ferrario et al., 2004). However, the current scientific and practical evidence on family situations and the services that families receive from professional services is often unsystematic and incomplete in targeting support for family situations (Thomas et al., 2010). This applies in particular to home-based palliative care in Germany, where in recent decades, a wide range of comprehensive palliative home care services have been developed. In 2016, Germany had approximately 1,500 palliative home care and hospice services, and 295 special palliative home care services (Deutscher Hospiz- und PalliativVerband e.V., 2016). These services care for about half of the 850,000 dying people per year (1% of the overall population), along with the family

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members involved (3–5% of the overall population) (Statistisches Bundesamt, 2016). One approach to assessing family situations at home may be to focus on the satisfaction of families with special palliative home care services (Ringdal, Jordhoy, Kaasa, 2002). To our knowledge, satisfaction is regarded as the most important indicator of the quality of palliative care and its correlation to the quality of life of families (Kaasa, Loge, 2003). In general, satisfaction with palliative care services is dependent on several elements, for example: communication, emotional support and consultation over decision-making (Dy et al., 2008). These elements should be adequately considered, so that professionals can make a positive impression on families within the palliative care situation (Mularski et al., 2007). In a preliminary work (Galatsch et al., 2015) we identified, several instruments containing these elements, but most have not been adapted to and validated in the German care context. The comparison of available and practicable instruments by Galatsch and colleagues (2015) shows that the FAMCARE-2 (17 items) (Aoun et al., 2010) has received special attention in both the research and practice of palliative care services in the past years. This instrument has been used to measure family satisfaction with professional care for a range of palliative care settings, for instance, acute care, hospice and home care, as well as for family members of cancer and non-cancer patients.

Aim

Satisfaction with services delivered by home-based palliative care teams has yet not been sufficiently investigated in Germany. To the best of our knowledge, while a pilot study in Germany was recently conducted using the FAMCARE-2 in clinical settings (Sewtz et al., 2014), our current study is the first with emphasis on home-based palliative care services in Germany. Therefore, the aim of this study was to apply the FAMCARE-2 in Germany for evaluating family caregiver satisfaction with home-based palliative care services.

Methods

Design

A cross-sectional study.

Sample

A convenience sample was recruited in a two-step method. First, palliative teams and palliative networks in North Rhine-Westphalia (NRW) (the most populous federal state in the west of Germany, with 17,865,516 residents (Statistisches Bundesamt,

2016) from the directory of the Alpha (Information Centre of palliative care services for NRW, <http://alpha-nrw.de>) were contacted, and 49 of the 123 teams agreed to participate in our study.

Recruitment was then targeted on professionals (physicians, nurses, etc.) from the 49 teams recruited for the study sample. This was through an information flyer, or through information sessions held locally for the purpose of this research project. Data was collected through the use of a 71-item paper questionnaire. Seven validated instruments were used. In total, 830 family members were contacted, and 106 agreed to participate in the anonymous survey, and returned the questionnaires, giving a response rate of 12.7%. The inclusion criteria were: (1) adults (aged 18 and over); (2) family members who are responsible for caring; (3) German language speaking.

Data collection

One part of the overall questionnaire was the FAMCARE-2 Scale. The FAMCARE-2 (Aoun et al., 2010) scale includes 17 items, and is available in German (Sewtz et al., 2014). The items refer to measures of satisfaction with the services delivered by palliative care teams with an interdisciplinary focus. Each item has a five-point Likert scale that ranks from *very dissatisfied*, *dissatisfied*, *undecided*, *satisfied* and *very satisfied*. In addition, the family members could select an additional option, “not relevant to my situation”. The scoring system of the scale can be shown in percentage distribution (satisfied or dissatisfied), or the mean score for each item, ranging from 1 to 5 (a high score indicating high satisfaction). The scale consists of four dimensions: 1. management of physical symptoms and comfort (five items); 2. provision of information (four items); 3. family support (four items); and 4. patient psychological care (four items) (for details of the items, please see Table 2). In this current study, the FAMCARE-2 scale achieved a Cronbach’s α of 0.90. The higher the score, the more reliable the scale. As a general rule of thumb, an alpha of 0.90 or higher is considered excellent, and 0.50 or less is considered unacceptable (Bortz, Döring, 2006).

Sociodemographic information

Several sociodemographic items were used to collect information on age, gender, country of birth, highest level of education, occupation, and the relationship between patient and carer. These items were identified in a preliminary work as important factors within the palliative family situation (Galatsch et al., 2015).

Data analysis

Following the established statistical approaches by Aoun (2010), descriptive statistics on demographic characteristics were first performed. Responses to each item, the overall FAMCARE-2 mean score, the four-dimension mean scores, and the average item mean scores, together with standard deviations, were then calculated. In order to examine the relationships between demographic variables and family caregiver satisfaction, analysis of variance (ANOVA) was utilized to test the differences in overall satisfaction, as well as the four dimension scores, according to the demographic groups. Multiple testing was verified with the Hochberg GT2 method.

Results

Descriptive profile of Family Caregivers

The demographic characteristics of the family caregivers (n = 106) are shown in Table 1. More than one-third of the family caregivers were female (67.9%) and living in partnerships (79.3%). The mean age of family caregivers was 58.3 (range 33–82) years. The family members who cared for patients were predominately spouses (48.1%) or children (34.9%). In 77.3% of all cases, two or more people shared responsibility for patients. Most of the family caregivers (75.5%) were classed as having a lower education (less than academic high school).

Scores of FAMCARE-2

As seen in Table 2, the overall satisfaction score in our sample was high (mean 62.96). This holds true for the mean scores of the four FAMCARE-2

dimensions: “Management of physical symptoms and comfort” (mean 18.580); “Provision of information” (mean 14.40); “Family support” (mean 15.10); and “Patient psychological care” (mean 15.63) all indicated high satisfaction.

Regarding the distribution of item response, the general pattern revealed that more than half of participants were satisfied or very satisfied, and less than a quarter expressed scores of dissatisfied or very dissatisfied. Notably, the highest percentage of satisfaction was found in item 4: “The way in which the palliative care team respect patient dignity” (84.0%); item 8: “The ways in which patients’ physical needs for comfort are met” (84.0%); and item 17: “Emotional support provided to patients by the palliative care team” (80.2%).

Whereas item 1: “Patient comfort” (24.5%); and item 3: “Information given about the side effect of treatment” (23.6%) showed the highest proportion of dissatisfaction in the sample.

Differences of the overall FAMCARE-2 and four dimensions scores by socio demographic groups

Family members aged 51–65 reported the lowest overall satisfaction (mean 58.8; p = 0.0012), compared to the group aged 50 or younger. However, no differences regarding age were found in dimension 3: “Provision of information”. In terms of gender, the only significant difference was found in dimension 4: “Patient psychological care”,

Table 1 Demographic profile of family caregivers

Respondents (n = 106)		n (%)
Age	50 or younger	37 (34.9)
	51–65	32 (30.2)
	66 or older	28 (26.4)
	missing	9 (8.5)
Gender	female	72 (67.9)
	male	34 (32.1)
Relation to patient	spouse/partner	51 (48.1)
	child	37 (34.9)
	other	16 (15.1)
	missing	2 (1.9)
Marital status	single	21 (19.8)
	partnership	84 (79.3)
	missing	1 (0.9)
Education	no academic High school	80 (75.5)
	academic High school	26 (24.5)
Responsible caregivers	only one person	22 (20.8)
	two persons	72 (67.9)
	more than two persons	10 (9.4)
	missing	2 (1.9)

Table 2 Response distribution of each item and scores of FAMCARE-2

Item	Item description	Response (%)			Not relevant	Not answered	Item mean score** (SD)	Overall /Dimension mean score*** (SD)
		5 / 4*	3*	2 / 1*				
FAMCARE-2 Overall satisfaction score (n = 90, range 17–85)							62.96 (8.92)	
Dimension 1: <i>Management of physical symptoms and comfort</i> ** (n = 100, range 5–25)							18.58 (2.82)	
1	The patient's comfort	55.7	18.9	24.5	0	0.9	3.24 (0.99)	
6	Speed with which symptoms are treated	64.2	16.0	14.2	0.9	4.7	3.58 (0.88)	
7	Palliative care team's attention to the patient's description of symptoms	75.5	18.9	2.8	0	2.8	4.05 (0.86)	
8	The way in which the patient's physical needs for comfort are met	84.0	8.5	4.7	0	2.8	3.93 (0.72)	
12	The Doctor's attention to the patient's symptoms	72.6	12.3	13.2	0	1.9	3.81 (0.91)	
Dimension 2: <i>Provision of information</i> ** (n = 102, range 4–20)							14.40 (2.99)	
2	The way in which the patient's condition and likely progress have been explained by the palliative care team	69.8	9.4	19.8	0	0.9	3.59 (0.96)	
3	Information given about the side effects of treatment	40.6	34.0	23.6	0	1.9	3.27 (0.94)	
5	Meetings with the palliative care team to discuss the patient's condition and plan of care	64.2	28.3	5.7	0	1.9	3.83 (0.92)	
14	Information given about how to manage the patient's symptoms (e.g. pain, constipation)	61.3	18.9	17.0	0	2.8	3.68 (1.01)	
Dimension 3: <i>Family support</i> ** (n = 94, range 4–20)							15.10 (2.56)	
9	Availability of the palliative care team to the family	73.6	10.4	14.1	0	1.9	3.89 (0.98)	
10	Emotional support provided to family members by the palliative care team	72.7	9.4	16.0	0	1.9	3.75 (0.93)	
11	The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	71.8	16.0	2.8	7.5	1.9	3.84 (0.91)	
13	The way the family is included in treatment and care decisions	70.8	12.3	13.2	0.9	2.8	3.76 (0.89)	
Dimension 4: <i>Patient psychological care</i> ** (n = 102, range 4–20)							15.63 (2.39)	
4	The way in which the palliative care team respects the patient's dignity	84.0	11.3	2.8	0	1.9	4.12 (0.71)	
15	How effectively the palliative care team manages the patient's symptoms	67.0	23.6	6.6	0	2.8	3.77 (0.78)	
16	The palliative care team's response to changes in the patient's care needs	68.9	22.6	4.8	0.9	2.8	3.85 (0.78)	
17	Emotional support provided to the patient by the palliative care team	80.2	9.4	7.6	0	2.8	3.90 (0.75)	

*Very Satisfied (5), Satisfied (4), Neither (3), Dis-satisfied (2), Very dis-satisfied (1); **Mean ranges from 1 to 5, where 5 represents highest satisfaction;

***Dimension scores are the sum of item scores

in which men reported higher satisfaction. Family caregivers living in partnerships reported higher satisfaction in “overall” FAMCARE-2 score, dimension 3: “Family Support”, and dimension 4: “Patient psychological care”. Regarding responsible

family caregivers, the group with two people gave a significantly lower overall satisfaction rating for dimension 3: “Family support” than families where more than two people were responsible for care of a dying person.

Table 3 Differences in the overall FAMCARE-2 and four dimension scores by demographic groups

Items	Characteristics	Overall FAMCARE-2 satisfaction (range 17–85 [#]) mean (SD)	Dimension1: Management of physical symptoms and comfort [#] (range 5–25 [#]) mean (SD)	Dimension2: Provision of information (range 4–20 [#]) mean (SD)	Dimension3: Family support (range 4–20 [#]) mean (SD)	Dimension4: Patient psychological care (range 4–20 [#]) mean (SD)
Age		n = 82	n = 91	n = 94	n = 86	n = 94
		p = 0.0012#	p = 0.0028#	p = 0.0284#	p = 0.0001#	p = 0.0202#
	50 or younger (RG)	65.31 (9.40)	19.62 (3.02)	15.10 (2.80)	15.70 (2.35)	16.24 (2.60)
	51–65	58.50* (8.86)	17.38* (2.73)	13.40 (3.43)	13.70* (2.73)	14.70* (2.40)
	66 or older	66.40 (5.16)	18.90 (1.61)	15.16 (2.13)	16.41 (1.71)	15.84 (1.90)
Gender		n = 90	n = 100	n = 102	n = 94	n = 102
		p = 0.1380	p = 0.663	p = 0.5869	p = 0.0868	p = 0.0038#
	female (RG)	61.97 (9.55)	18.60 (3.01)	14.29 (3.20)	14.78 (2.60)	15.24 (2.62)
	male	64.93 (7.27)	18.56 (2.41)	14.64 (2.55)	15.74 (2.41)	16.47* (1.52)
Relation to patient		n = 88	n = 98	n = 100	n = 92	n = 100
		p = 0.8478	p = 0.0092#	p = 0.8166	p = 0.7722	p = 0.8327
	spouse/partner (RG)	62.21 (7.67)	17.69 (2.50)	14.34 (3.05)	15.26 (2.40)	15.66 (2.10)
	child	63.41 (8.37)	19.59* (2.72)	14.24 (2.94)	14.97 (2.07)	15.62 (2.40)
	other	63.00 (13.16)	18.63 (3.36)	14.81 (3.25)	14.73 (3.97)	15.30 (3.10)
Marital status		n = 89	n = 99	n = 101	n = 93	n = 101
		p = 0.0034#	p = 0.1642	p = 0.100	p = 0.0001#	p = 0.0150#
	single (RG)	57.80* (6.61)	17.81 (2.46)	12.90 (2.47)	13.10* (2.17)	14.78 (1.94)
	partnership	64.33 (9.01)	18.78 (2.91)	14.79 (3.03)	15.62 (2.41)	15.88 (2.34)
Education		n = 90	n = 100	n = 102	n = 94	n = 102
		p = 0.4651	p = 0.4816	p = 0.378	p = 0.2485	p = 0.3457
	no academic High school	62.56 (8.99)	18.45 (2.56)	14.24 (3.08)	15.26 (2.61)	15.51 (2.30)
	academic High school (RG)	64.25 (8.78)	19.00 (3.51)	14.92 (2.70)	14.52 (2.38)	16.04 (2.70)
Responsible cares		n = 88	n = 98	n = 100	n = 92	n = 100
		p = 0.0154#	p = 0.6892	p = 0.0300#	p = 0.0004#	p = 0.0687
	only one person	64.53 (6.01)	18.53 (2.32)	15.21 (2.07)	15.94 (1.70)	15.79 (1.40)
	two persons	61.45* (8.49)	18.46 (2.67)	13.92 (2.93)	14.48* (2.55)	15.32 (2.45)
	more than two persons (RG)	70.63 (13.22)	19.30 (4.64)	16.33 (4.33)	17.88 (2.30)	17.22 (2.90)

#indicate the overall significance level; *indicate a significance difference with the reference group (RG)

Discussion

The objective of this study was to examine the satisfaction of family caregivers with professional palliative home care. First, we found a generally high satisfaction in all dimensions of the FAMCARE-2. Our findings are in line with most studies that investigate the satisfaction of family caregivers with palliative care services. The high satisfaction of family caregivers in this research field has been confirmed, not only by contemporary studies (Aoun et al., 2010; Can et al., 2011), but also by studies which investigated caregiver satisfaction retrospectively (Fakhoury, McCarthy, 1998; Smeenk et al., 1998; Exley, Tyrer, 2005; Kealey, McIntyre,

2005; Hudson, 2006; O'Connor et al., 2009; Hannon et al., 2013). One reason for this could be that some families rated the palliative home care situation more positively compared to the negative experiences they underwent in hospitals (Cannaerts, de Casterle, Grypdonck, 2000). Having someone to “keep an eye on things” and support the family caregivers in their responsibility for patients seem plausible explanations for the high satisfaction within the complex palliative home care situation (Grande, Todd, Barclay, 1997). As suggested, support from special palliative services, or consultations with the services, were positively correlated with high satisfaction, thus fulfilling family-caregivers

emotional and spiritual needs (Gelfman, Meier, Morrison, 2008; Bee, Barnes, Luker, 2009). Consequently, this might indicate that families have a positive attitude towards the palliative care service. However, behind this high satisfaction, it is possible that some other needs of the families have not been met. The “hidden” needs could have an impact on the palliative care situation for the families. The FAMCARE-2 Scale allows a systematic and feasible overview of these needs. In the dimensions and items of the FAMCARE-2 Scale, we uncovered different topics and groups within the sample.

According to the sociodemographic characteristics, the group of middle-aged family caregivers (51 to 65 years) showed the lowest level of satisfaction in the overall FAMCARE-2 score, and in all dimensions, except dimension 3: “Family support”, whereas the group with the oldest family caregivers (66 or older), had the highest satisfaction in this sample. This high satisfaction of older family caregivers has been observed in many other studies worldwide (Medigovich et al., 1999; Smith, 2000; Ringdal, Jordhøy, Kaasa, 2002; Can et al., 2011). One explanation for this phenomenon could be that older family caregivers who take responsibility for other older family members rated the service more positively than caregivers of younger family members (Kristjanson, 1993; Medigovich et al., 1999). Our study lends support to this assumption. Unlike other studies (Medigovich et al., 1999; Ringdal, Jordhøy, Kaasa, 2002; Can et al., 2011) we did not find significant differences between genders. The group of men in our study had a slightly higher satisfaction rate than the group of women. One explanation might be that women perceive more stress or burden due to the fact they receive less support from the family when providing care to other family members (Brazil et al., 2009). In addition, several studies describe differences in satisfaction according to family-members’ education (Kristjanson, 1993; Medigovich et al., 1999; Ringdal, Jordhøy, Kaasa, 2002), as well as the lower satisfaction with services among adult children of a dying parent (Ringdal, Jordhøy, Kaasa, 2002). However, no such differences were found in our study. One reason might be that family caregivers could perceive higher satisfaction with the palliative care services regarding an elderly dying parent, as suggested by earlier studies (Kristjanson, 1993; Medigovich et al., 1999); however, the level of satisfaction of younger family caregivers was generally higher in our sample.

Notably, a closer look at the items shows that maintaining the comfort of dying family members poses a challenge to the palliative services. Item 1:

“Patient comfort” showed the highest proportion of dissatisfaction (24.5%) in this German sample. It could be that this lower satisfaction reflected the emotional pain of caregivers witnessing their family members going through the process of dying. Nevertheless, other items, such as 4: “The way in which the palliative care team respects patients’ dignity”; 8: “The way in which patients’ physical needs for comfort are met”; and 17: “Emotional support provided to patients by the palliative care team”, had much higher ratings for satisfaction (more than 80%), indicating that the palliative services do meet the comfort needs of the dying. Furthermore, the dissemination of information about the side effects of treatments deserves attention, as this is an area in which family members were less satisfied. Item 3: “Information given about the side effects of treatment” had the lowest percentage of “very satisfied/satisfied” (40.6% only) among all items of the FAN CARE-2 scale. Side effects appear to be an important issue, making family members feel fearful and helpless (Hinds, 1992; Hanson, Danis, Garrett, 1997; Lau et al., 2010). Dissemination of information and psychological support, especially for such negative events such as side effects, are of great importance to families (Hileman, Lackey, Hassanein, 1992; Hinds, 1992; Addington-Hall, McCarthy, 1995; Gelfman, Meier, Morrison, 2008; Stajduhar et al., 2011), given the fact that family members evaluate symptoms as significantly worse than professionals (Higginson, Wade, McCarthy, 1990). Therefore, it is crucial for palliative services to offer individual practical training and educational consultations for family members, and to adjust the content of these resources continuously to suit the unique needs of families (Hudson, 2009).

Limitations of study

To the best of our knowledge, this is the first study in Germany reflecting a wide range of palliative home care services, using data from multiple sites. On the other hand, several limitations need to be considered. First, the response rate of our study was not high. The low response could be due in part to the vulnerability of those in a palliative care situation, and it is understandable that families might not wish to participate in such a study. However, the sample size of our study seemed sufficient to generate meaningful findings, compared to previous studies (Can et al., 2011; Ringdal, Jordhøy, Kaasa, 2002). Second, since the sample collection was based on a two-step convenience sample, we had little control over whether the sample was chosen at random. Due to the nature of questionnaire surveys relying on self-reported data common method bias

and recall bias on the observed associations cannot be ruled out. In addition, methodological challenges in measuring satisfaction in palliative care should be mentioned (Ringdal et al., 2002; Ringdal et al., 2003; Aoun, 2010). These challenges, based on existing literature, include social desirability, meaning that caregivers may be answering in the way they believe is expected of them through subjective variability in defining satisfactory care; unwillingness to criticize the palliative services, and, possibly, fear of discrimination should they report low levels of satisfaction (Lo et al., 2009). Finally, it was unknown at what stage of the dying process families participated in our study. As a result, we could not check whether the palliative care services had preselected in their distribution of questionnaires.

Conclusion

High or low satisfaction with palliative care, tells us little about the quality of services. The high satisfaction in this study could also be interpreted as a sign that palliative care was important to families at the moment of availability. However, it must not be forgotten that it is the families who are continuously involved in the care of their relatives.

The FAMCARE-2 Scale could serve as a screening tool in early palliative care, and may also be systematically applied to obtain an initial and continuous assessment of the family situation.

Ethical aspects and conflict of interest

This study was approved by the Ethical Committee of the German Society of Nursing Science (DGP) in January 2013, and was performed in accordance with the Helsinki Declaration. Written informed consent was obtained from each participant. We have no conflict of interest to declare.

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Author contribution

Conception and design (MG), data collection (MG), data analysis and interpretation (MG, JL), manuscript draft (MG, JL), critical revision of the manuscript

(MG, JL, FSW, WS), final approval of the manuscript (MG, JL, FSW, WS).

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