



Caregivers' satisfaction with cervical cancer care in Ethiopia

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Abstract

Background and purpose Cervical cancer is the second most common cancer among African women, following breast cancer. Palliative care is among the standards of care in cancer management. While caregivers play key roles in palliative care, their satisfaction with the care influences treatment outcomes and patients' quality of life. This study evaluated caregivers' satisfaction with the care provided to patients with advanced cervical cancer.

Method A cross-sectional evaluation of caregivers' satisfaction with patient care was conducted at a tertiary hospital in Ethiopia. The study tool included the 20-item family satisfaction with advanced cancer care (FAMCARE) and caregiver stress index (CSI). Using binary logistic regression, we identified factors associated with caregivers' satisfaction.

Result A total of 360 caregivers were interviewed. Most of the caregivers were male (58.1%), below the age of 35 years (60.8%), and educated to the high school level or less (64.4%). The average FAMCARE score was 77.7 out of the maximum 100. High satisfaction was observed among subscales "availability of treatment and care" and "psychosocial care," while low satisfaction was observed with "physical patient care" and "provision of information." Caregivers' stress and time dedicated to the caregiving were associated with caregivers' satisfaction.

Conclusion Overall, high satisfaction with advanced care at the tertiary hospital was documented. However, the caregivers also bore high burden of strain. Management of caregivers' strain, prompt treatment of patients' symptoms, and provision of adequate information to the caregivers could further improve caregivers' satisfaction.

Keywords Caregivers · Caregiver stress index · Caregivers' satisfaction · Cervical cancer · FAMCARE · Palliative care

Introduction

Caregivers play a key role in providing comprehensive palliative care [1, 2]. The increasing trend in the prevalence and chronicity of cancer have led to unmet need for palliative care that requires the involvement of family caregivers [3, 4]. Caregivers support the patients in their daily activities and encourage them to utilise treatment and care effectively. While they play a crucial role in the treatment and care, caregivers themselves suffer from a high burden of challenges [5]. The caregivers could face stress and anxiety resulting from persistent symptoms burden, poor prognosis of the disease, poor quality of care, lack of socio-economic support,

and distressing body images resulting from the disease or its treatment [6]. Studies show that 10% of the population are affected by depressive symptoms and poor quality of life resulting from chronic diseases and the loss of their friends and families [7].

Comprehensive palliative care includes treatment of pain and other symptoms, socio-economic support, and spiritual care to the patients, families, and caregivers [4, 8, 9]. Improving patients' and caregivers' quality of life and satisfaction with the treatment and care are central to the standards of palliative care among patients with cancer [10–14]. Satisfaction with palliative care among caregivers is key to improving the patients' quality of life [5]. In contrast, dissatisfaction and stress among caregivers can lead to mental disorders and poor quality of life among the patients [7, 15–17].

Caregivers' satisfaction with the patient care can be a proxy indicator for effective palliative care services and the quality of life [18]. Supporting the caregivers and improving their quality of life are also key components of comprehensive palliative care [4, 10].

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Various factors affect caregivers' satisfaction with patient care. These include perception of care, adequate privacy for patients, sufficient pain relief, accessibility of the care, good communication with the patients and caregivers, emotional support, and involvement of the patients and caregivers in the decision-making process [10, 19]. The stage of the disease, visits by healthcare workers, and patient functional status also affect caregivers' satisfaction [20]. In turn, patient satisfaction is also affected by caregiver satisfaction [21].

Different tools are in place to measure the satisfaction of family caregivers with the palliative care provided to patients with chronic, life-threatening diseases. Family satisfaction with advanced cancer care (FAMCARE) is the most widely used scale [21]. The validity and reliability of the tool have been proven acceptable [21].

This study evaluated the satisfaction of family caregivers of patients with advanced cervical cancer at a specialised hospital in Ethiopia. We also described the characteristics of the caregivers and the burden of the stress associated with caregiving.

Methods

Design and setting

The study included a cross-sectional design conducted among randomly selected patients diagnosed with advanced cervical cancer (stage IIB–IVB) in a tertiary hospital in Addis Ababa, Ethiopia, from January to June 2019. Information on socio-demographic characteristics of the caregivers, the stage of the disease, and two standardised scales, the FAMCARE [22, 23] and the caregiver stress index (CSI) [24], were included in the study. This manuscript is part of a PhD project at the University of South Africa (UNISA), from which the study design and sampling technique have been published elsewhere [25].

Data collection and ethics

Data collection was conducted after obtaining ethical approvals from the UNISA and the Institutional Review Board of Addis Ababa University. A total of 385 patients diagnosed with advanced cervical cancer attending a tertiary hospital in Ethiopia from January to June 2019 were randomly selected [25]. Caregivers accompanying the selected patients during the hospital visits were interviewed using a structured and pretested questionnaire. A caregiver was defined as a family or informal caregiver who cared for the patient, mainly at home and assisted them during the hospital visit. The principal researcher conducted the interview, assisted by trained hospital nurses. The caregivers also

provided informed consent before the interview. The confidentiality of the data was maintained throughout.

Study tools

The questionnaire included the FAMCARE having 20 items with a five-level Likert Scale ranging from 1 representing “very dissatisfied” to 2 “dissatisfied,” 3 “undecided,” 4 “satisfied,” and 5 “very satisfied.” The proportion of caregivers satisfied with care was computed by recoding 5 and 4 to “yes” and the other responses to “no.” The items were categorised into four sub-scales: availability of treatment and care, physical patient care, psychosocial care, and information provision. The satisfaction scores and the mean and standard deviation of the items and the aggregate scales were computed. Factor variables included caregiver characteristics, relationship with the patients, time spent for caregiving in hours per week, duration since the start of the caregiving, stage of the disease, and CSI score.

The caregivers' strain burden was measured using the CSI, which constituted 13 items coded with “1” for “yes” and “0” for “no” responses. The aggregate CSI score was computed by adding scores of the 13 items. The aggregate score, ranging from 0 (no stress) to 13 (bearing all the stresses), was recoded into three categories: 0–3 for minimum strain burden, 4–6 for moderate strain burden, and 7–13 for high strain burden.

Data analysis

Data collected from the caregivers were entered and cleaned using CS Pro version 7.1 and transferred to Stata 12 for analyses. Data analyses included computation of frequency distribution with number and percentage, mean, and standard deviation in the descriptive analysis. Logistic regression was used to identify factors associated with caregivers' satisfaction using a statistical significance at *p*-value less than 0.05.

Results

A total of 360 primary caregivers of patients diagnosed with advanced cervical cancer were interviewed during the follow-up visit to a tertiary hospital in Addis Ababa, Ethiopia. The mean and interquartile range for age were 34 and 52, respectively. Most of the caregivers were male ($n = 209$, 58%), aged below 35 years ($n = 219$, 60.8%), and educated secondary school or lower ($n = 232$, 64.4%) (Table 1).

Nearly half of the caregivers ($n = 179$; 49.7%) were currently married, while 46.1% ($n = 166$) were single. About one-third of the caregivers ($n = 119$; 33.1%) were the patients' parents, while 26.9% ($n = 97$) were their children. Spouses constituted only 13.6% ($n = 49$), whereas siblings

Table 1 Characteristics of caregivers of patients with advanced cervical cancer, 2019

Caregiver characteristics	Number (n)	Percent (%)
Gender		
Male	209	58.1
Female	151	41.9
Age group		
Below 35 years	219	60.8
35+ years	141	39.2
Education		
Secondary education or lower	232	64.4
Higher education or above	128	35.6
Marital status		
Married	179	49.7
Single	166	46.1
Dissolved marriage	15	4.2
Occupation		
Employee	140	38.9
Small trade	70	19.4
Student	45	12.5
Farmer	30	8.3
Others*	75	20.8
Relationship		
Parent	119	33.1
Child	97	26.9
Spouse	49	13.6
Sibling	28	7.8
Other relatives and friends	67	18.6
Stage of the disease		
Stage II(B)	83	23.1
Stage III (A, B)	95	26.4
Stage IV (A, B)	182	50.5
Time spent for caregiving (per week)		
12 h or less	95	26.4
13–36 h	80	22.2
37 hours or above	185	51.4
Duration of caregiving		
1 year or less	253	70.3
2–4 years	86	23.9
5 years or above	21	5.8
Caregiver stress index		
High burden (7–13)	261	72.5
Moderate burden (4–6)	68	18.9
Minimum burden (0–3)	31	8.6

*Includes retired and no job

were 7.8% ($n=28$). Other relatives and friends have also constituted a significant proportion ($n=67$, 18.6%). Occupation of the caregivers varied from employees ($n=140$; 38.9%), petty traders ($n=70$; 19.4%), and farmers ($n=30$, 8.3%). Students, retired caregivers, and those with no jobs

also constituted a significant amount (Table 1). Most of the patients they cared for were at stage IV ($n=182$, 50.5%), followed by stage III ($n=95$, 26.4%), and II ($n=83$, 23.1%). Most caregivers spent over 36 h per week for caring. The average time spent on caregiving was 2.5 days per week for an average of 1.5 years.

The average and standard deviation of the CSI was 8.5 ± 3.1 . A high proportion of the caregivers ($n=261$, 72.5%) were in the high burden group, ranging from 7 to 13 on the CSI scale. A smaller proportion ($n=31$, 8.6%) was bearing a minimal burden, 0–3 CSI score, whereas 68 (18.9%) were bearing a moderate burden, with a 4–6 CSI score (Table 1).

The mean aggregate FAMCARE, constituting the sum of the 20 items, was $77.7(\pm 15.4)$ out of 100, which shows higher satisfaction with the care (see Table 2). Two sub-scales, psychosocial care and availability of care, showed higher satisfaction scores with a mean and standard deviation of 4.1 ± 0.9 and 4.0 ± 0.9 , respectively. Lower satisfaction was scored for information provision and physical patient care with mean and standard deviation of 3.6 ± 1.0 and 3.9 ± 0.9 , respectively (see Table 2). The proportion of caregivers who responded in agreement with the items (responses 4–5) was computed and presented in Table 2.

Respondents were the least satisfied with the time taken to reach the diagnosis, information given on side effects of the treatments, and information given regarding management of the patient's pain (see Fig. 1). Caregivers' satisfaction with the speed with which symptoms were treated, availability of hospital beds, and information regarding the patient's prognosis was also low. Most caregivers were satisfied with the availability of nurses to the caregivers and doctors to the patients. Communication with caregivers to discuss the illness also showed a good level of satisfaction. Table 2 and Fig. 1 compare different items and sub-scales with mean scores and proportions.

Covariates of caregivers' satisfaction with cancer care

The aggregate score of FAMCARE was compared by socio-demographics of the caregivers, stage of the disease, time spent for the caregiving, duration since the start of the caregiving, and strain associated with the caregiving. No significant variation in caregivers' satisfaction was observed by gender, education, marital status, occupation, patient relationship, and disease stage. Although higher satisfaction scores were documented among caregivers above 35 years, the difference was not statistically significant (see Table 3).

Caregivers who provided care for more than a year have a higher mean FAMCARE score than those who cared for a shorter time (79.8 vs 75.6); however, the difference was not statistically significant. A significant association was observed

Table 2 Caregivers' satisfaction with patient care, 2019

FAMCARE-20 Subscales and items	Mean (SD)	Satisfaction ^a
Availability of treatment and care		
Availability of hospital bed	3.6 (1.4)	53.9
Availability of doctors to the family/caregiver	4.1 (1.1)	73.9
Availability of nurses to the family/caregiver	4.2 (1.0)	80.1
Availability of the doctor to the patient	4.2 (1.1)	77.3
Sub-scale aggregate score	4.0 (0.9)	
Physical patient care		
The patient's pain relief	4.0 (1.2)	72.5
Referrals to specialists	4.1 (1.2)	74.7
Speed with which symptoms are treated	3.5 (1.5)	58.1
Doctor's attention to the patient's description of symptoms	4.2 (1.1)	83.1
The way tests and treatments are performed	4.0 (1.3)	73.0
Time required to make a diagnosis	3.2 (1.4)	46.1
The way tests and treatments are followed up by the doctor	4.2 (1.1)	78.9
Sub-scale aggregate score	3.9 (0.9)	
Psychosocial care		
Communication with family/caregiver to discuss the illness	4.1 (1.2)	74.7
Coordination of care	3.9 (1.2)	67.5
The way the family/caregiver is included in treatment and care decisions	4.1 (1.1)	78.3
How thoroughly the doctor assesses the patient's symptoms	4.2 (1.1)	78.1
Sub-scale aggregate score	4.1 (0.9)	
Information provision		
Information provided about the patient's prognosis	3.6 (1.4)	58.8
Answers from health professionals	4.0 (1.2)	73.1
Information given about side effects	3.3 (1.4)	50.9
Information given about how to manage the patient's pain	3.5 (1.4)	58.9
Information given about the patient's tests/test results	3.8 (1.3)	66.1
Sub-scale aggregate score	3.6 (1.0)	
Overall aggregate (sum of 20 items, scored out of 100)	77.7 (15.4)	

SD, standard deviation; FAMCARE, family satisfaction with advanced cancer care

^asatisfaction, in %, is recoded from responses with 4 = "satisfied" or 5 = "very satisfied"

between time dedicated to caregiving and caregivers' strain. A multivariable logistics model, reporting odds ratio (OR), also revealed that the time provided for the caregiving (OR: 0.58 [0.37, 0.90], $p=0.016$) and the caregiver stress (OR: 0.93 [0.86, 0.99], $p=0.036$) were the two independent factors associated with the FAMCARE score (see Table 3). Caregivers who dedicated less than 24 hours a week and those with less strain were more satisfied with hospital-level care for the patients.

Discussion

In this study, caregivers' satisfaction with patient care at a tertiary hospital was assessed using FAMCARE—the first study of its kind in this setting. The study also determined

who the caregivers of patients with cervical cancer were and the strain burden they bore. The study documented that most caregivers were either satisfied or strongly satisfied with the treatment and care at the tertiary hospital, with an average score of 77.7 out of a maximum 100. However, low satisfaction was documented with the provision of adequate information, time taken to reach the diagnosis, the speed with which symptoms were treated, and the availability of hospital care. This study showed a comparable level of satisfaction with research conducted in Japan [7]; however, it was higher than the study conducted in Spain [5].

Most caregivers (60%) were parents and children compared to other studies in which spouses predominated (over 75%) [2, 7, 10]. In addition, most of the caregivers were male in this study; in contrast, various studies reported

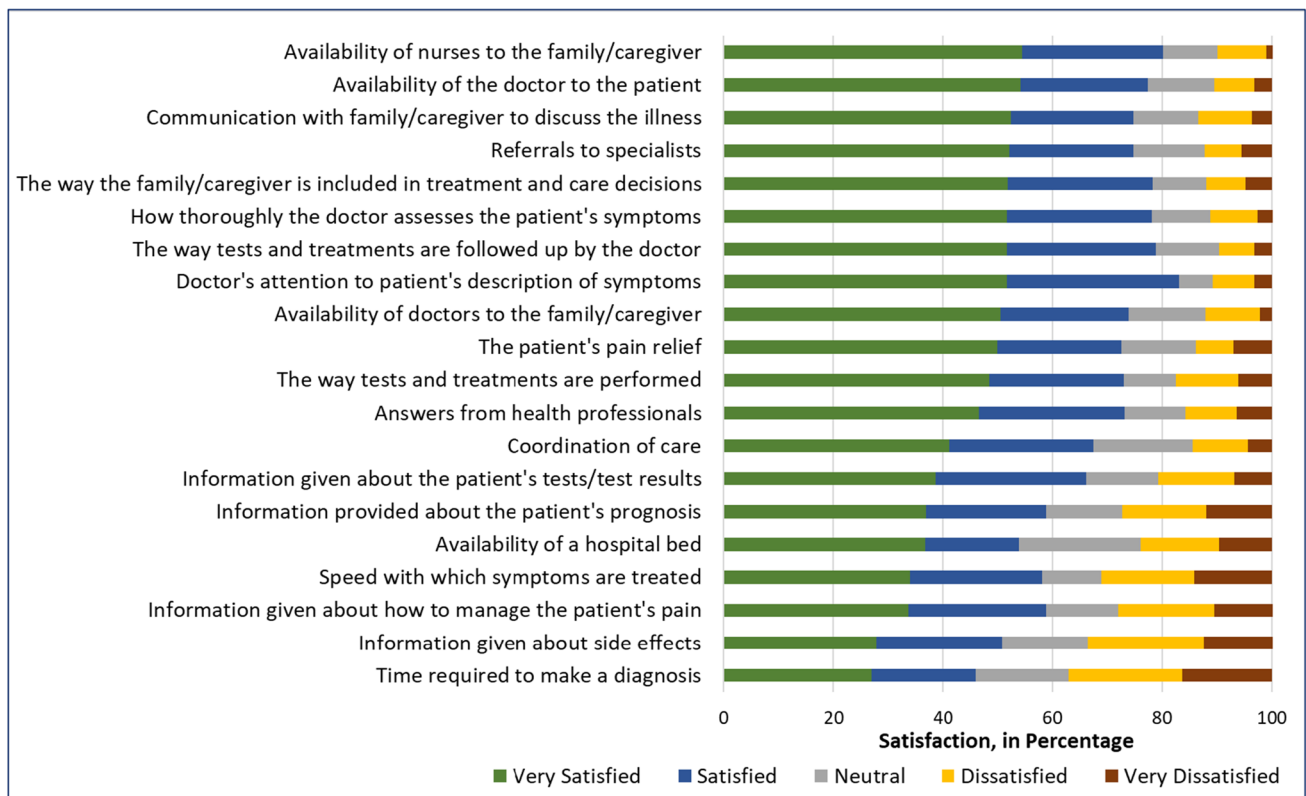


Fig. 1 Caregivers' satisfaction with hospital care using the FAMCARE Scale, 2019. SD, standard deviation; FAMCARE, family satisfaction with advanced cancer care

predominantly female caregivers [2, 5, 7, 10, 26]. However, a study in India reported that most caregivers were male [15].

Socio-demographic characteristics such as age, gender, education, marital status, occupation and relationship with the patients were not associated with caregivers' satisfaction with the care in this study. However, some studies reported variations by age [7], education, occupation, marital status, and quality of care [2, 10, 19, 27, 28]. In this study, time dedicated to caregiving and caregiver strain were the two independent factors associated with satisfaction with the advanced hospital treatment and care. The caregivers spent an average of 60 hours per week, equivalent to daily 8.5 hours, supporting the patients. Caregivers who spent more time on patient care showed less satisfaction with the hospital care.

The strain affects caregivers' and patients' overall physical and emotional health [15, 16]. In this study, caregivers' strain burden was high; 72.5% had a high burden. A study conducted in India among caregivers of patients with cancer also reported a high-stress burden of 82% and less satisfaction with patient care [15].

This study provided the caregivers' satisfaction with the hospital care among patients diagnosed with cervical

cancer and caregivers' strain, using the FAMCARE and CSI, for the first time in the setting. This information would be important for designing and evaluating palliative care interventions targeting families and caregivers.

This study has a limitation. The setting for the interview of the caregivers was a hospital. In addition, hospital nurses have assisted the selection of the participants and the data collection process. These could have introduced some level of social desirability bias. However, the bias might have been minimised since the study utilised standardised and validated tools, the FAMCARE and CSI.

Conclusions

Caregivers of patients diagnosed with cervical cancer demonstrated a good overall satisfaction with treatment and care at the tertiary hospital. However, less satisfaction was reported with the time taken to make the diagnosis, availability of hospital beds, speed with which symptoms were treated, and provision of adequate information. Therefore, strengthening the provision of information to the caregivers and prompt management of symptoms could improve caregivers' satisfaction. Satisfaction with care was better

Table 3 Covariates of caregivers' satisfaction, 2019

Variables	FAMCARE score Mean (SD)	Bivariate logistic regression OR [CI]	Multivariable logistic regression	
			OR [CI]	P value
Age				
Below 35 years	76.1 (15.7)	1.00	1.00	
35 + years	80.2 (14.6)	1.50 [0.98, 2.30]	1.47 [0.85, 2.53]	0.167
Gender				
Male	77.9 (15.9)	1.00	1.00	
Female	77.4 (14.7)	0.86 [0.57, 1.31]	0.84 [0.52, 1.35]	0.469
Education				
≤ Secondary school	77.3 (16.3)	1.00	1.00	
Higher education	78.5 (13.6)	0.87 [0.56, 1.34]	0.87 [0.54, 1.39]	0.553
Marital				
In marital union	77.7 (16.3)	1.00	1.00	
Not in marital union	77.7 (14.5)	1.00 [0.66, 1.51]	0.85 [0.52, 1.37]	0.492
Occupation				
Has a job	77.1 (16.0)	1.00	1.00	
No job	78.9 (14.1)	0.90 [0.58, 1.40]	0.93 [0.57, 1.51]	0.779
Relationship				
Spouse	79.4 (17.9)	1.00	1.00	
Parent	75.6 (15.0)	0.65 [0.34, 1.28]	0.99 [0.43, 2.25]	0.973
Child	78.7 (15.7)	0.87 [0.43, 1.73]	1.29 [0.56, 2.98]	0.550
Other relatives and friends	78.4 (14.1)	0.80 [0.40, 1.59]	1.08 [0.49, 2.39]	0.852
Time spent for caregiving				
≤ 24 h per week	79.9 (14.0)	1.00	1.00	
> 24 h per week	74.7 (16.6)	0.53 [0.35, 0.81]**	0.58 [0.37, 0.90]*	0.016
Duration of caregiving				
< 1 year	75.6 (16.2)	1.00	1.00	
≥ 1 year	79.8 (14.3)	1.43 [0.94, 2.16]	1.46 [0.94, 2.28]	0.093
Stage of cancer				
II (B)	79.2 (15.6)	1.00	1.00	
III (A, B)	78.0 (14.8)	0.90 [0.50, 1.62]	1.12 [0.60, 2.09]	0.714
IV (A,B)	76.8 (15.7)	0.71 [0.42, 1.19]	0.85 [0.49, 1.48]	0.568
Caregiver strain index (CSI) scale				
	-0.134* ^a	0.91 [0.85, 0.97]**	0.93 [0.86, 0.99]*	0.036

Associations with statistical significance (p -value < 0.05) are shown in bold

SD, standard deviation; OR, odds ratio; CI, confidence interval; FAMCARE, family satisfaction with advanced cancer care

*Statistically significant difference at 0.05; **statistically significant difference at 0.01; ^aPearson's correlation coefficient

among caregivers who demanded less time for caregiving and among caregivers with less strain burden. Palliative care interventions need to target alleviating strain among the caregivers of patients with cervical cancer. Such palliative care can improve the patients' quality of life and the satisfaction of families and caregivers.

Abbreviations CSI: Caregiver stress index; FAMCARE: Family satisfaction with advanced cancer care; OR: Odds ratio; UNISA: University of South Africa

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Author contribution TK conducted research design, data collection, cleaning, and analysis. TK, AM, and AHM conducted the write-up of this research article. All authors have reviewed and approved the final version of this manuscript.

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Data availability This study is part of the principal author's PhD project at UNISA. The dataset collected and analysed in this study is available from the corresponding author upon reasonable request and after UNISA grants permission.

Declarations

Ethics approval The Institutional Review Board of the College of Health Sciences, Addis Ababa University, granted ethical approval for this research (PN-058/18/IM). All the methods performed were in accordance with the relevant guideline and regulations. The Research Ethics Committee, Department of Health Studies of the UNISA, also approved this research. In addition, the Radiotherapy Centre also provided written permission. The result of the study was organised using the Strengthening the Reporting of Observational Studies in Epidemiology guideline.

Consent to participate All the study participants have received information regarding the research and provided informed consent before the interview.

Consent to publish This is not applicable. This report does not include individuals' information, images, or videos.

Competing interests The authors declare that they have no competing interests.

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