

# Family Caregivers Perceptions of Patient's Symptom Burden and Satisfaction with Palliative Care Services in a Tertiary Care Center in Saudi Arabia

Steven Callaghan, MSN, RN<sup>1\*</sup>, Gassan Abudari, MSN(c), RN<sup>2</sup>, Kim Sadler, PhD, BSN<sup>1</sup>, Muneerah Almutairi, MSN<sup>3</sup>, Fawad Ahmad, MBBS, MD<sup>4</sup>, Wafa Alalwani, BSN, RN<sup>5</sup>

<sup>1</sup>Advanced Clinical Specialist Nurse, Oncology Nursing Department, King Faisal Specialist Hospital & Research Center, Riyadh, Saudi Arabia

<sup>2</sup>Clinical Nurse Specialist, Oncology Nursing Department, King Faisal Specialist Hospital & Research Center, Riyadh, Saudi Arabia

<sup>3</sup>Head Nurse, Oncology Nursing Department, King Faisal Specialist Hospital & Research Center, Riyadh, Saudi Arabia

<sup>4</sup>Medical Consultant, Oncology Center of Excellence, King Faisal Specialist Hospital & Research Center, Riyadh, Saudi Arabia

<sup>5</sup>Staff Nurse, Oncology Nursing Department, King Faisal Specialist Hospital & Research Center, Riyadh, Saudi Arabia

DOI: [10.36348/sjnhc.2024.v07i01.004](https://doi.org/10.36348/sjnhc.2024.v07i01.004)

| Received: 05.12.2023 | Accepted: 14.01.2024 | Published: 30.01.2024

\*Corresponding author: Steven Callaghan

Advanced Clinical Specialist Nurse, Oncology Nursing Department, King Faisal Specialist Hospital & Research Center, Riyadh, Saudi Arabia

## Abstract

This study aimed to explore the family caregivers (FCs) perception of patients' symptom burden as well as their experience and satisfaction with specialized palliative care services (PCS) in a tertiary care center in Kingdom of Saudi Arabia (KSA).

**Methods:** A cross-sectional design assessed patients known to the PCS in a tertiary care center in Saudi Arabia from May 2023 to September 2023. FCs perceptions of patient's symptom burden and satisfaction with PCS were studied through the *Family Satisfaction with End-of-Life Care Scale* (FAMCARE-2) and *Arabic Questionnaire for Symptom Assessment* (AQSA). **Results:** A convenience sample of 264 FCs agreed to participate (response rate = 94%). Approximately half of the participants were male (n=146; 55.7%). Participants were mostly aged between 30 to 50 years (n =148; 56%). Approximately half were receiving disease-modifying treatments. 101 (38.3%) had a Do-Not-Attempt-Resuscitation (DNAR) order. There was high satisfaction with how the services respected the dignity FCs (M = 4.6; SD=0.6). FCs were less satisfied with 'the practical assistance provided by the PCS' (M = 4.1; SD = 0.9). Satisfaction was higher in the outpatient setting (M = 4.3, SD = 0.7). The most severe symptom reported by FCs was 'tiredness', followed by 'pain'. The mildest ones were 'shortness of breath', followed by 'nausea/vomiting'. **Conclusion:** Overall, FCs have reported a positive experience with inpatient and outpatient PCS. FCs' greater satisfaction was observed in the outpatient setting with the possible rationale that inpatients are often more unstable and symptomatic.

**Keywords:** family caregivers (FCs) perception, palliative care services (PCS), satisfaction, shortness of breath.

**Copyright © 2024 The Author(s):** This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CC BY-NC 4.0) which permits unrestricted use, distribution, and reproduction in any medium for non-commercial use provided the original author and source are credited.

## INTRODUCTION

The Kingdom of Saudi Arabia (KSA) with a population of 37 million reports 3.5 deaths per 1000 individuals yearly [1]. Over the past decades, healthcare has significantly evolved with a focus on improving services, infrastructures, and recruiting expertise. Globally, cardiovascular disease remains the world's leading cause of mortality with an estimated 17.9 million deaths in 2019, representing 32% of all global deaths [2]. In 2020, cancer accounted for nearly 10 million deaths. The most common types are breast, lung, colon, rectal, and prostate cancers [3]. These patients require complex

multidimensional care throughout their disease trajectory, whether they are receiving treatments aimed at cure or palliative care services (PCS) focused on comfort.

By addressing suffering whether physical, psychological, social, or spiritual, palliative care improves the quality of life of patients and families facing challenges associated with potentially life-limiting conditions [3, 4]. In KSA, Palliative Care as a specialty was first established in 1992 at King Faisal Specialist Hospital and Research Center/Riyadh, becoming the first recognized service in the Middle East

[5]. Since then, PCS have evolved across the country. However, a growing and aging population, coupled with a subset of inhabitants difficult to reach due to extensive land areas, challenges countrywide implementation. Most PCS are still concentrated around the larger cities of Riyadh, Jeddah, and Dammam. Providing accessibility to PCS with a focus on building interdisciplinary working forces is one of the healthcare goals of KSA 2030 Vision. Enabling and supporting family caregivers (FCs), whether through educational programs, material and financial resources, or improved coordination across care settings, is an important strategy to achieve this goal.

Advances in treatments led to increasingly more complex and numerous patients' and families' needs [6]. Palliative care prides itself on providing services to the patient and FCs, with both seen as equally important [7]. Therefore, FCs should be considered as members of the patient's care team and need to be cared for as well. If often rewarding through a feeling of fulfillment, joy, and a sense of duty to care for a loved one during a time of sickness [8], the FCs role also comes with long hours and the physical and psychological burden of seeing someone close unwell [9]. Measuring FCs' perception of satisfaction with PCS allows FCs to share their experience and allow healthcare providers to better understand if PCS are meeting the needs.

## AIM

This study aimed to explore the family caregivers' perception of patients' symptom burden as well as their experience and satisfaction with specialized palliative care services in a tertiary care center in KSA.

## METHODS

The study was conducted at King Faisal Specialist Hospital and Research Center (KFSH&RC) in Riyadh, KSA. This is a tertiary care hospital that holds a Joint Commission International (JCI) accreditation as an Academic Medical Centre and an American Nurses Credentialing Centre (ANCC) Magnet® designation. PCS range from complex symptom control to psychological, social, and spiritual support. The team comprises of specialized physicians and nurses, supported by dedicated healthcare professionals. PCS are provided across inpatient and outpatient settings (including Home Care Service).

### Study design

A cross-sectional design was used to survey FCs of patients receiving specialized adult PCS (patients with an age of 14 years or above) at KFSH&RC/R from May 2023 to September 2023.

### Population

The inclusion criteria were: 1) to be a caregiver of a patient followed by the adult PCS for a minimum of 3 encounters (inpatient, outpatient), 2) to be aged 18 years or above, and 3) to have the capacity to consent and

fill a questionnaire independently. A convenient sampling method was used.

### Sample size

A previous study conducted by Kondeti *et al.* (10) with a sample size of 211 and a similar methodology showed that a total mean score of 74 from a possible final score of 85 indicated high satisfaction with the PCS. Based on this study and an approximation of 500 patients receiving specialized PCS at a given point at KFSH&RC/R, using a significance criterion of  $\alpha = 0.05$  and a confidence interval of 95%, the minimum sample size was calculated to be 218. 20% was added to account for natural attrition, thus the final sample size was 262.

## Instruments

### 1. Family Satisfaction with End-of-Life Care Scale (FAMCARE-2)

The FAMCARE-2 is a 17-item validated scale developed by Aoun *et al.*, [11] that measures FCs' satisfaction with healthcare professionals delivering PCS. The FAMCARE-2 is a modified version of the original FAMCARE developed by Kristjanson *et al.*, [12]. The tool was used in a range of care settings as well as for FCs of patients with malignant or non-malignant conditions. It includes four subscales: management of physical symptoms and comfort, provision of information, family support, and patient psychological care. All 17 items are rated on a 5-point Likert scale (from 1=very satisfied to 5=very dissatisfied). Reliability and validity were deemed adequate [11]. Pidgeon *et al.*, [13] (Australia) surveyed 1,592 caregivers from 49 services on their satisfaction with PCS. Results indicated high satisfaction. Zu Sayn Wittgenstein-Hohenstein [14] (Germany) and Kondeti *et al.*, [10] (India) obtained similar results: high levels of satisfaction with PCS with a viewpoint that the FAMCARE-2 was a useful measure. Consent was acquired to use the tool from the original authors. The survey was translated into Arabic by a medical translator.

### 2. Arabic Questionnaire for Symptom Assessment (AQSA)

The AQSA is a tool assessing 12 common physical and emotional symptoms, specifically pain, tiredness, nausea/vomiting, anxiety, depression, shortness of breath, drowsiness, insomnia, dry mouth, loss of appetite, and confusion. Patients, caregivers, or healthcare providers can rate their intensity on a 0 to 10 visual numerical scale. Validity and reliability were found to be adequate [15].

## ETHICAL APPROVAL

Ethics approval was received from the Institutional Board Review of KFSH&RC/R (#2231090). A waiver for signed consent was granted and the verbal consent process was documented in patients' electronic medical records.

## RESULTS

### Family Caregivers and Patients' Sociodemographic Characteristics

A total of 264 FCs participated in the study (response rate = 94%). Four questionnaires were rejected as deemed too incomplete. Approximately half of the participants were male ( $n=146$ ; 55.7%). Participants were mostly aged between 30 to 40 years ( $n = 75$ ; 28.4%) or between 40 to 50 years ( $n = 73$ ; 27.6%). A majority had a university degree ( $n = 186$ ; 70.4%). Most FCs were the patient's child ( $n=123$ ; 46.6%) followed equally, by the patient's parent or spouse ( $n = 35$ ; 13.3%). Both genders were represented equally. Patients' mean age was 53.2 years ( $SD = 16.9$ ) ( $Mdn = 55.8$  years). Nearly half of the FCs/patients lived in the central region. Additional data can be found in Tables 1 and 2.

An independent *t*-test showed a statistically significant difference in satisfaction with PCS between male FCs ( $M=4.3$ ,  $SD=0.7$ ) and females ( $M=4.0$ ,  $SD=0.8$ ),  $t(260) = 2.4$ ,  $p = 0.1$ . Males were more satisfied than women. Additionally, a one-way ANOVA showed a difference in FCs mean satisfaction according to the residence location [ $F(4, 259) = 2.8$ ,  $p = 0.02$ ]. Patients living in the Western region had lower satisfaction with PCS ( $M = 3.8$ ,  $SD = 1.2$ ). No other differences were found for sociodemographic variables.

### Patients' Clinical and Treatments Characteristics

The majority of patients had cancer ( $n = 254$ ; 96.2%). Approximately half were receiving disease-modifying treatments such as chemotherapy ( $n = 143$ ; 54.1%). 101 (38.3%) had a Do-Not-Attempt-Resuscitation (DNAR) order. The mean number of encounters with PCS was 11 visits with a mean period of 209 days between the first and last recorded encounter (inpatient, outpatient clinic, home care). FCs were recruited predominantly in palliative care clinics ( $n = 172$ ; 65.1%). Additional data can be found in Table 3.

FCs were more satisfied with the PCS for patients receiving concurrent disease-modifying treatments ( $M=4.3$ ,  $SD = 0.7$ ) rather than strict PCS ( $M = 4.0$ ,  $SD = 0.8$ ),  $t(262) = 2.3$ ,  $p = 0.02$ . However, no difference was found whether the patient had a DNAR order or not.

### Family Caregivers' Assessment of Patients' Symptom Burden

Using the *Arabic Questionnaire for Symptom Assessment* (AQSA), the most severe reported patients' symptoms by FCs were 'tiredness' ( $M = 5.86$ ;  $SD = 3.0$ ), followed by 'pain' ( $M = 5.7$ ;  $SD = 3.0$ ). The mildest ones were 'shortness of breath' ( $M = 2.6$ ;  $SD = 2.9$ ) followed

by 'nausea/vomiting' ( $M = 3$ ;  $SD = 3.1$ ). More data on other reported severe symptoms can be found in Figure 1.

A weak correlation between FCs' reports of patients' symptoms and FCs satisfaction final scores on the FAMCARE-2 was found, whereas the highest correlation was for the 'loss of appetite' ( $r=0.19$ ) and the lowest for 'nausea/vomiting' ( $r=0.002$ ).

### Family Caregiver's Care Satisfaction with Palliative Care Services

On the four FAMCARE-2 subscales, no correlations were found across patients' and caregivers' sociodemographic data and patients' clinical and treatment data (Table 4). Once the scores from the FAMCARE-2 17 items are summed up, a final score ranging between 17 and 85 is obtained. Higher scores refer to better satisfaction with PCS. In this study, the FAMCARE-2 final mean score for the whole sample ( $N = 264$ ) was 74.2 ( $SD = 14.4$ ) indicating good care satisfaction. The item with the highest rating referred to FCs satisfaction with 'how the PCS respects the patient's dignity' ( $M = 4.6$ ;  $SD=0.6$ ). FCs were less satisfied with 'the practical assistance provided by the PCS' ( $M = 4.1$ ;  $SD = 0.9$ ). All item responses can be found in Table 4.

There was a significant FCs satisfaction mean score difference according to care settings [ $F(2, 261) = 4.33$ ,  $p=0.014$ ]. Satisfaction was higher in the outpatient setting ( $M = 4.3$ ,  $SD = 0.7$ ) than in the inpatient setting (Consultation service) ( $M = 3.9$ ,  $SD = 0.5$ ) ( $p = 0.2$ ). However, no difference was found between the outpatient setting and inpatient setting when the Palliative Care Team was the treating service ( $M = 4.0$ ,  $SD = 0.7$ ).

A multiple linear regression was performed to determine predictors of FCs care satisfaction with PCS. Four predictors were included in the model: 'care setting', 'FCs gender', 'presence of disease-modifying treatments, and 'residence location'. The overall model was statistically significant,  $F(4, 257) = 3.956$ ,  $p = 0.004$ , suggesting that the predictors, as a set, reliably distinguished between the values of the satisfaction mean score. The care setting and FCs' gender were found to be adequate predictors. The 'care setting' showed a positive association with the FCs satisfaction mean score with an unstandardized coefficient (B) of 0.180. The standardized coefficient (Beta) was 0.134. This predictor was statistically significant with  $t(257) = 2.021$ ,  $p = 0.044$ . Furthermore, the 'FCs gender' demonstrated a negative relationship with the satisfaction mean score, with  $B = -0.210$  and  $Beta = -0.134$ . This relationship was statistically significant,  $t(257) = -2.199$ ,  $p = 0.029$ .

**Table 1: FCs' Sociodemographic Characteristics and FAMCARE-2 Final Scores**

<b>Family Caregivers</b>				
	<i>n</i>	%	<i>FAMCARE-2 Mean Final Score</i>	<i>SD</i>
<b>Gender<sup>a</sup></b>				
Female	116	44.3	74.9	11.2
Male	146	55.7	74.0	11.7
<b>Age group (years)</b>				
18-30	58	22	75.6	12.0
31-40	75	28.4	73.9	10.8
41-50	73	27.7	74.1	11.5
51-60	33	12.5	72.2	10.7
<b>Highest educational level</b>				
Elementary school	10	3.8	76.6	9.5
Secondary school	63	23.9	74.0	10.6
University	186	70.5	73.3	12.3
Uneducated	5	1.9	80.5	9.5
<b>Relation to patient</b>				
Spouse	35	13.3	74.0	11.3
Parent	35	13.3	72.7	11.7
Child	123	46.6	73.6	11.3
Other	32	12.1	75.9	11.2

Note. *N* = 264. <sup>a</sup> Caregiver gender (*n* = 262, due to missing data for 2 patients)

**Table 2: Patients' Sociodemographic Characteristics and FAMCARE-2 Final Scores**

<b>Patients</b>				
	<i>n</i>	%	<i>FAMCARE-2 Mean Final Score</i>	<i>SD</i>
<b>Gender</b>				
Female	148	56.1	74.0	11.2
Male	116	43.9	74.6	11.7
<b>Marital status</b>				
Single	47	17.8	74.6	11.5
Married	178	67.4	74.3	11.5
Divorced/Separated	17	6.5	73.1	12.8
Widowed	22	8.3	71.9	10.7
<b>Place of residence</b>				
Central	125	47.3	73.3	10
North	30	11.4	76.8	9.8
South	61	23.1	74.8	11.3
East	24	9.1	76.3	10
West	18	36	67.8	12.1

Note. *N* = 264. Patients' age on average 53 years old (*SD* = 16.9); *Mdn* = 55.8

**Table 3: Patients' Clinical, Treatments Characteristics and FAMCARE-2 Final Scores**

<b>Patients</b>				
	<i>n</i>	%	<i>FAMCARE-2 Mean final score</i>	<i>SD</i>
<b>Diagnosis</b>				
Cancer	254	96.2	74.7	11.3
Non-malignant condition	10	3.8	70.5	12.7
<b>Currently receiving disease-modifying treatments</b>				
Yes	143	54.2	73.7	11.2
No	121	45.8	74.8	11
<b>Resuscitation status</b>				
Full code	163	61.7	74.6	11.2
DNAR <sup>a</sup>	101	38.3	73.9	11.7
<b>Care setting</b>				
Inpatient (Primary Service)	12	4.5	70.2	11.9
Inpatient (Consultation only)	80	30.3	69.3	9
Outpatient	172	65.2	75.9	11.9
<b>Palliative Care Services (PCS)</b>				
Number of encounter(s)	<i>M</i> = 10.7			
Duration of Follow Up <sup>b</sup>	<i>M</i> = 209 days			

Note. *N* = 264. <sup>a</sup> Do-Not-Attempt-Resuscitation; <sup>b</sup> Mean duration in days between the first and last recorded encounter with PCS

**Table 4: Family Caregivers FAMCARE-2 Item Responses and Item Mean Scores**

Item	Very Satisfied %	Satisfied %	Neither Satisfied nor Dissatisfied %	Dissatisfied %	Very Dissatisfied %	Item mean score	SD	
1	54.5	32.2	8.3	2.6	1.5	4.37	0.48	
6	52.6	28.8	12.5	3	1.5	4.30	0.48	
7	64	26.5	6.4	1.5	0.8	4.53	0.49	
8	58.7	29.2	7.2	2.6	0.8	4.45	0.41	
12	58.7	31.8	4.5	2.3	1.5	4.46	0.48	
SUBSCALE: PROVISION OF INFORMATION								
2	56.4	31.4	9.1	1.5	1.1	4.41	0.48	
3	50.4	33.3	10.2	3.8	0.8	4.31	0.46	
5	49.6	28.4	13.3	4.2	1.5	4.45	0.47	
14	53.8	34.8	6.4	2.6	1.1	4.45	0.46	
SUBSCALE: FAMILY SUPPORT								
9	50.4	22.7	14.8	3	1.9	4.26	0.43	
10	45.8	26.1	16.7	3.4	0.8	4.22	0.49	
11	35.6	20.8	15.5	3	1.1	4.14	0.49	
13	50	29.9	9.8	3.8	0.4	4.33	0.48	
SUBSCALE: PATIENT PSYCHOLOGICAL CARE								
4	74.6	20.8	2.3	0	1.1	4.67	0.51	
15	52.6	35.2	7.9	1.9	1.1	4.38	0.45	
16	54.5	32.6	9.8	0.8	1.1	4.40	0.46	
17	54.5	28	11.4	2.6	1.5	4.34	0.46	

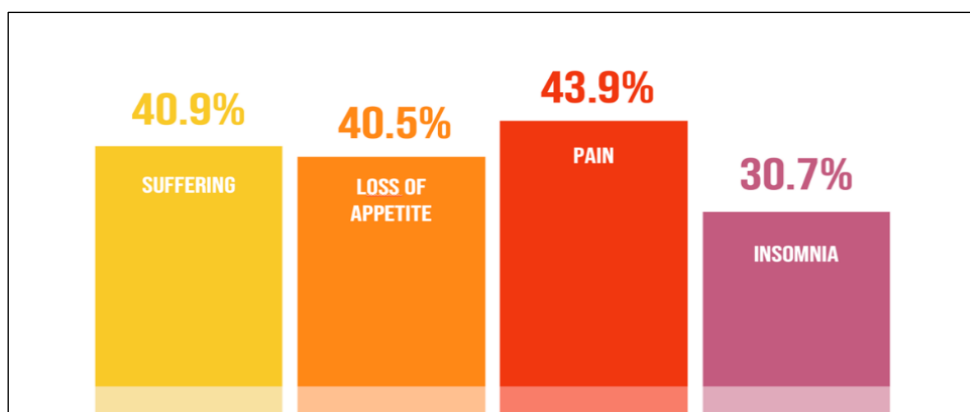


Figure 1: FCs Reported Mean Scores for Pain and Other Symptoms on the AQSA  
 Note. *n* = 116 (Male); *n* = 148 (Female)

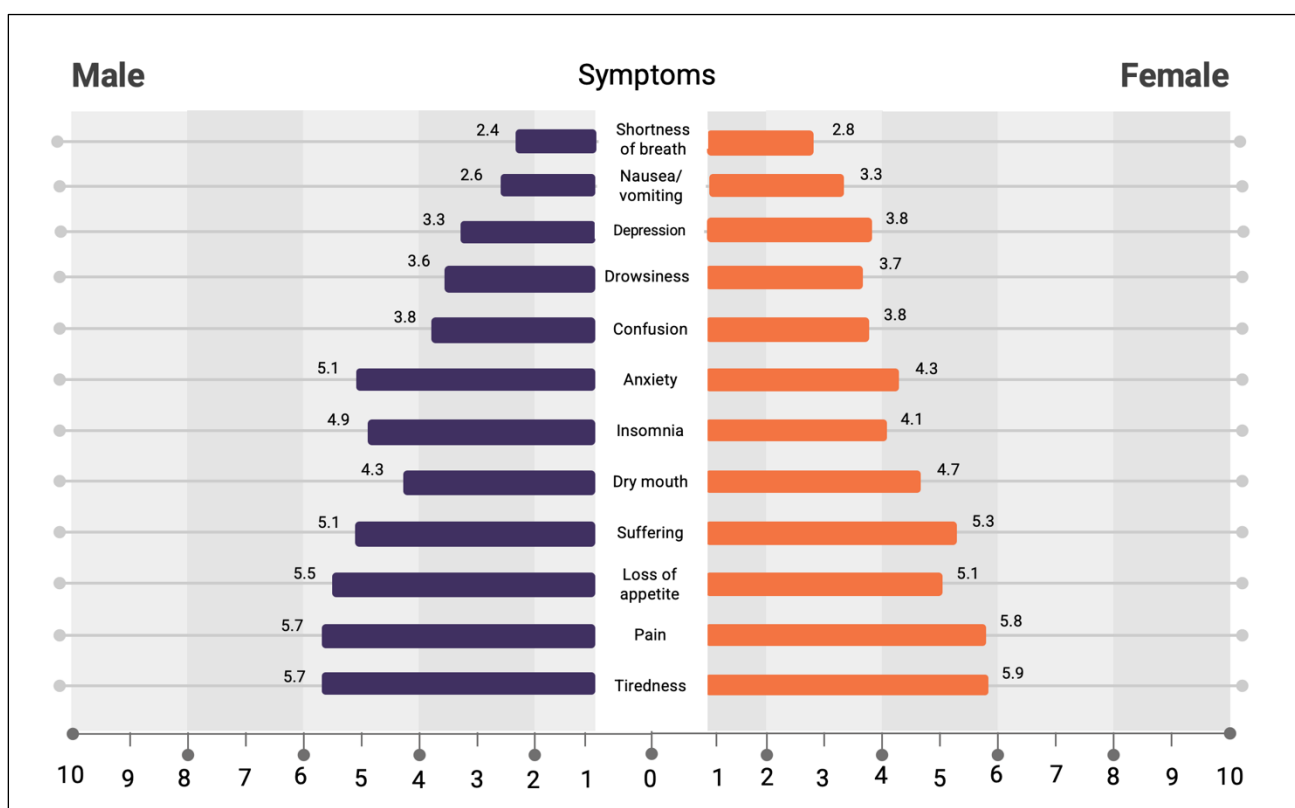


Figure 2: FCs Reported Severity of Severe Pain and Other Symptoms

## DISCUSSION

This study sought to assess from the FC's perspective the patient's symptom burden, the satisfaction with PCS, and if correlations existed between these two aspects. Results from the FAMCARE-2 were analyzed across sociodemographic, clinical, and treatment variables.

### Family Caregivers and Patients' Sociodemographic Characteristics

Male FCs showed higher satisfaction with PCS compared to females. A study exploring FCs satisfaction with home-based PCS provided the same finding [14]. Lower satisfaction was found for patients residing in the

Eastern region of KSA. At this stage, no explanations can be provided to explain these specific findings.

### Patients' Clinical and Treatments Characteristics

The overwhelming majority of patients had a cancer diagnosis (*n* = 254) with 54.2% and were receiving disease-modifying treatments. Cancer and treatments affect not only patients but also FCs [16]. Receiving concurrent disease-modifying treatments may have influenced FCs' satisfaction with PCS by giving FCs a stronger 'sense of hope'. FCs might have felt less distressed thinking that a cure was still possible. Pain and symptom control are a priority for the patient and FCs [17]. Oncology teams often liaise with PCS regarding patients' symptom burden as uncontrolled symptoms may have a direct impact on which treatments can be

offered [18]. In that sense, this could have influenced FCs satisfaction scores. On the other hand, when goals of care are strictly focused on comfort care, in addition to providing pain and symptom control, PCS must invest much more in their other roles: coordination between care settings, emotional and psychosocial support, flexibility regarding follow up when patients can no longer travel to the hospital, advanced care planning, anticipatory grief preparation. These roles might not have brought enough satisfaction in the current study for FCs to give scores as high as when their family member was still receiving disease-modifying treatments.

### Family Caregivers' Assessment of Patients' Symptom Burden

Pain, loss of appetite, and insomnia were the most frequently reported symptoms by FCs. These findings align with other studies in the region. AlJaffar *et al.*, [19] reported fatigue as the most experienced symptom with a cancer diagnosis. In four centers ( $n = 246$ ), Abu-Helalah *et al.*, [20] reported that fatigue, pain, and insomnia were the most frequent symptoms in women with breast cancer. Imran *et al.*, [21] (KSA) reported that insomnia and fatigue were the most distressing symptoms, followed by pain and loss of appetite ( $n = 284$ ). Nageeti *et al.*, [22] found fatigue and sleeping difficulties were the most frequent as well. Alzahrani *et al.*, [23] found that sleeping problems, weight gain, and fatigue were the most prevalent physical symptoms in a sample of breast cancer patients. In neighboring Bahrain ( $n = 239$ ), fatigue (35.28%), insomnia (30.12%), and pain (29.97%) were the most distressing [24]. In a multicenter study involving 17 centers (USA), pain, fatigue, and emotional distress were most prominent [25]. If these studies have assessed the severity of symptoms from the patient's perspective, the current study showed that FCs report the same symptoms. However, caution must prevail as shown previously FCs' subjectivity can affect judgment when assessing a patient's symptoms. FCs who feel significantly burdened by providing care tend to produce more discordant symptom assessments [26]. Moreover, the discordance between FCs and patients tends to be more pronounced for more subjective symptoms such as emotional distress compared to observable symptoms such as vomiting [26]. Nevertheless, whether using patient self-report measures or proxy-reported measures, these studies tell us that these symptoms are not systematically addressed. Many patients do not receive any support to mitigate the deleterious effects of fatigue on the quality of life for fatigue, a debilitating symptom affecting all patients diagnosed with cancer [19].

Findings regarding gender differences in terms of cancer-derived symptoms are inconclusive. Some reported that men have better overall functioning during their oncological treatment (KSA) [27] or that the female gender was associated with a poorer quality of life (KSA) ( $n = 276$ ) [19]. A large prospective, international, cross-cultural, multicenter study (Germany, Great Britain,

Italy, Israel, Norway, Poland, Spain, Taiwan, and Cyprus) ( $n = 200$ ) concluded that the typical quality of life gender difference effect (women doing worse than men) was not generalizable across all patient samples [28]. In the current study, despite apparent differences in symptom severity according to gender (Figure 1), no statistically significant differences were identified.

A weak correlation was found between FC's perceived loss of appetite and satisfaction with care. This could be explained in that a decrease in food intake might be a sign that is easily noticeable by FCs as opposed to more *invisible* symptoms like nausea or anxiety. A decrease in appetite, with its associated weight loss, is often perceived by FCs as a sign of disease progression and met with great distress as compared to other symptoms. Even when patients are at an advanced stage and a loss of appetite/weight is expected, FCs continue to react strongly and often 'pressure' clinicians to address the decreased oral intake. PCS's difficulty to address FCs concerns regarding the loss of appetite could lead to poorer care satisfaction scores.

### Family Caregiver's Care Satisfaction with Palliative Care Services

#### 1. Results FAMCARE-2 subscales and item analyses

No correlations were found between FAMCARE-2 subscales, sociodemographic, clinical, and treatment variables. On an item level, FCs were less satisfied with the poor pragmatic assistance provided by the PCS. Nowadays, patients and FCs have to navigate increasingly more complex healthcare systems. Pain and symptom control might be the most recognized role of PCS but for patients and FCs, the coordination role between care settings and different medical services is often voiced as a well-appreciated role. FCs want pragmatic help with matters such as assistance in dealing with bureaucratic procedures (e.g. equipment need request, reimbursements for care) [29]. FCs also stress the usefulness of having a clear contact point between the community and the hospital setting [29]. PC-specialized nurses often play this key role by allowing direct contact with FCs. FCs can then easily have answers regarding symptom control, assistance to adjust their medication, and access to emotional support. In a distressing and challenging time, this level of support is likely to ease their experience, which would ultimately reflect on the feedback from FCs on PCS quality.

A greater satisfaction with the care was observed in the outpatient setting. Pidgeon *et al.*, [30] study explored patients' levels of pain and other symptoms while receiving care from PCS and suggested that patients are often more unstable and symptomatic in the inpatient setting. For these patients followed by PCS, an admission often ends in a prolonged hospital stay due to uncontrolled symptoms and uncertainty of disease trajectory [6]. This would likely have an impact on FCs' physical and mental health. Lower levels of family

anxiety and depressed feelings were also found in the outpatient setting in other studies [30].

The overall absence of correlation between the FCs' reported symptom burden and the satisfaction of care is somewhat surprising. Considering the WHO Pain Ladder for the classification of pain, a score of 7-10/10 is considered *severe pain*. 43% of FCs reported that the patient was having severe pain. Using the same cutoff of 7/10, FCs reported severe total suffering for 40.9% of patients and severe insomnia for 30.7% (Figure 2). We would expect the satisfaction level with PCS to reflect a level of dissatisfaction considering that the mandate of PCS is to address these symptoms in question. The same phenomenon was observed in a previous study assessing the quality of life of adult patients receiving oncological treatments in KSA [27]. In a sample of 400 patients (all cancer types), 10.4% reported "very much" to having pain interfering with their daily activities, 24% severe constipation, and 31.5% significant sleeping difficulties yet, 80.3% reported being satisfied with the quality of information they received to manage their symptoms and 82.3% with the attention given to their symptoms by their physician. Social desirability and worries about the confidentiality of their answers may have influenced negatively the study results.

## LIMITATIONS

This is a single center study and the majority of patients had a cancer diagnosis. Symptoms are subjective and adding a patient self-reported measure would have been interesting to compare the results with the FCs ones. Additionally, methodological challenges while measuring FCs' satisfaction with services are well known. FCs may be reluctant to give negative feedback due to concerns over the confidentiality, social desirability, and the impression that giving low-level feedback may compromise patient care (Aoun *et al.*, 2010; Lo *et al.*, 2009; Ringdal *et al.*, 2003). Therefore, results are probably positively skewed toward positive satisfaction as filling the questionnaire in the clinic where PCS is received might have influenced the response choices.

## CONCLUSION

Overall, FCs have reported a positive experience with inpatient and outpatient PCS. FCs' greater satisfaction was observed in the outpatient setting with the possible rationale that inpatients are often more unstable and symptomatic. As in other studies, fatigue, pain, and loss of appetite were the most commonly reported symptoms and need to be better addressed. The highest rating of satisfaction was for PCS respect for patients' dignity whilst the less was for the 'practical assistance provided'. This indicates the need for PCS to optimize their coordination role and involve more systematically other healthcare providers, such as social workers, to provide integrated care addressing multidimensional needs. In addition, PCS need to ensure that they tailor their roles whether the patient is receiving

concurrent disease-modifying treatments or strict comfort care. Models of PCS simply cannot be replicated in other settings, especially from other countries with different healthcare delivery systems, socioeconomic contexts, and cultures. This study's findings suggest several practical applications in the realm of palliative care. Firstly, the development of enhanced communication protocols between healthcare providers and family caregivers is imperative, ensuring informed involvement in care decisions. Secondly, tailored support programs for caregivers, addressing their emotional and informational needs, are essential. Thirdly, healthcare professionals should receive specialized training to better understand and meet family caregivers' unique requirements. Additionally, these insights should inform policy development, emphasizing caregiver inclusion in service planning and delivery. Establishing community-based caregiver support networks and robust feedback mechanisms is also crucial, facilitating continuous improvement in palliative care services based on caregiver feedback. These recommendations aim to optimize palliative care by integrating family caregiver perspectives, thereby improving care quality and satisfaction.

## Ethical statement

Ethics approval was received from the KFHC&RC/R Office of Research Affairs (ORA) in May 2023. (# 2231090). A waiver for signed consent was granted.

## Sources of support and funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

**Declarations of interest:** The authors have no conflicts of interest to declare.

## ACKNOWLEDGMENT

The authors wish to express the family caregivers and KFSH&RC/R staff members who supported and/or participated in this study.

## Authors' Contribution

Study concept and design (SC, KS), Data collection (SC, GA, MA, WA), Data analysis (GA), Data interpretation (SC, GA, KS), Manuscript redaction (SC, KS, GA), final manuscript approval (All).

## REFERENCES

1. The Global Media Insight. (2022). Saudi Arabia Population Statistics 2022. Available Online at: <https://www.globalmediainsight.com/blog/saudi-arabia-population-statistics/>. Accessed 02/December 2022.
2. The World Health Organization. (2021). (Online) Available at: [https://www.who.int/news-room/fact-sheets/detail/cardiovascular-diseases-\(cvds\)](https://www.who.int/news-room/fact-sheets/detail/cardiovascular-diseases-(cvds)). Accessed 05 October 2023.



3. The World Health Organization. (2022). Cancer. (Online) Available at: <https://www.who.int/news-room/fact-sheets/detail/cancer>. Accessed 05 October 2023.
4. Rome, R. B., Luminais, H. H., Bourgeois, D. A., & Blais, C. M. (2011). The role of palliative care at the end of life. *Ochsner Journal*, 11(4), 348-352.
5. Zeinah, G. F. A., Al-Kindi, S. G., & Hassan, A. A. (2013). Middle East experience in palliative care. *American Journal of Hospice and Palliative Medicine*, 30(1), pp.94-99.
6. Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040? Past trends, future projections, and implications for services. *BMC Medicine*, 15(1), 1-10.
7. McIlvennan, C. K., & Allen, L. A. (2016). Palliative care in patients with heart failure. *Bmj*, 353.
8. Maree, J. E., Moshima, D., Ngubeni, M., & Zondi, L. (2018). On being a caregiver: The experiences of South African family caregivers caring for cancer patients. *European Journal of Cancer Care*, 27(2), p.e12801.
9. Kagan, I., Tsamir, J., & Engelchin Nissan, E. (2023). Public views on healthcare workers' burnout before and during COVID-19: A comparative study. *Journal of Nursing Scholarship*.
10. Kondeti, A. K., Yadala, A., Lakshmi, N. R., Prakash, C. S. K., Palat, G., & Varthya, S. B. (2021). Assessment of Caregiving Burden of Family Caregivers of Advanced Cancer Patients and Their Satisfaction with the Dedicated Inpatient Palliative Care Provided to Their Patients: A Cross-Sectional Study from a Tertiary Care Centre in South Asia. *Asian Pacific Journal of Cancer Prevention: APJCP*, 22(7), 2109.
11. Aoun, S., Bird, S., Kristjanson, L. J., & Currow, D. (2010). Reliability testing of the FAMCARE-2 scale: measuring family carer satisfaction with palliative care. *Palliative medicine*, 24(7), 674-681.
12. Kristjanson, L. J. (1993). Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care. *Social Science & Medicine*, 36(5), 693-701.
13. Pidgeon, T. M., Johnson, C. E., Lester, L., Currow, D., Yates, P., Allingham, S. F., & Egar, K. (2018). Perceptions of the care received from Australian palliative care services: A caregiver perspective. *Palliative & supportive care*, 16(2), 198-208.
14. zu Sayn-Wittgenstein-Hohenstein, F., Galatsch, M., Li, J., & Schnepf, W. (2017). Family Caregiver Satisfaction With Home-Based Palliative Care Services In North Rhine-Westfalia, Germany. *Central European Journal of Nursing and Midwifery*, 8(4), 723-730.
15. Al-Shahri, M. Z., Al-Zahrani, A. S., Alansari, A., Abdullah, A., Alshaqi, M., Matar, A., ... & Sroor, M. Y. (2017). Validation of an Arabic questionnaire for symptom assessment. *American Journal of Hospice and Palliative Medicine*, 34(4), 358-365.
16. LeSeure, P., & Chongkham-Ang, S. (2015). The experience of caregivers living with cancer patients: a systematic review and meta-synthesis. *Journal of personalized medicine*, 5(4), 406-439. doi: 10.3390/jpm5040406.
17. Johnson, M. J. (2009). The principles of symptom control. *British Journal of Hospital Medicine*, 70(4), pp.186-187.
18. Von Roenn, J. H., & Temel, J. (2011). The integration of palliative care and oncology: the evidence. *Oncology*, 25(13), p.1258.
19. AlJaffar, M. A., Enani, S. S., Almadani, A. H., Albuqami, F. H., Alsaleh, K. A., & Alosaimi, F. D. (2023). Determinants of quality of life of cancer patients at a tertiary care medical city in Riyadh, Saudi Arabia. *Frontiers in Psychiatry*, 14, p.1098176.
20. Abu-Helalah, M., Mustafa, H., Alshraideh, H., Alsuhaib, A. I., Almously, O. A., Al-Abdallah, R., Shehri, A. A., Al Qarni, A. A., & Al Bukhari, W. (2022). Quality of life and psychological well-being of breast cancer survivors in the Kingdom of Saudi Arabia. *Asian Pacific Journal of Cancer Prevention: APJCP*, 23(7), p.2291.
21. Imran, M., Al-Wassia, R., Alkhayyat, S. S., Baig, M., & Al-Saati, B. A. (2019). Assessment of quality of life (QoL) in breast cancer patients by using EORTC QLQ-C30 and BR-23 questionnaires: A tertiary care center survey in the western region of Saudi Arabia. *PloS one*, 14(7), p.e0219093.
22. Nageeti, T. H., Elzahrany, H. R., Gabra, A. O., Obaid, A. A., & Jastania, R. A. (2019). Quality of life assessment of breast cancer patients in Saudi Arabia. *Journal of family & community medicine*, 26(2), p.98.
23. Al Zahrani, A. M., Alalawi, Y., Yagoub, U., Saud, N., & Siddig, K. (2019). Quality of life of women with breast cancer undergoing treatment and follow-up at King Salman Armed Forces Hospital in Tabuk, Saudi Arabia. *Breast Cancer: Targets and Therapy*, 199-208. doi: 10.2147/BCTT.S200605.
24. Jassim, G. A., & Whitford, D. L. (2013). Quality of life of Bahraini women with breast cancer: a cross-sectional study. *BMC cancer*, 13(1), pp.1-14.
25. Smith, T. G., Troeschel, A. N., Castro, K. M., Arora, N. K., Stein, K., Lipscomb, J., Brawley, O. W., McCabe, R. M., Clauser, S. B., & Ward, E. (2019). Perceptions of patients with breast and colon cancer of the management of cancer-related pain, fatigue, and emotional distress in community oncology. *Journal of Clinical Oncology*, 37(19), p.1666.
26. McPherson, C. J., Wilson, K. G., Lobchuk, M. M., & Brajtman, S. (2008). Family caregivers' assessment of symptoms in patients with advanced cancer: concordance with patients and factors affecting accuracy. *Journal of pain and symptom management*, 35(1), pp.70-82.
27. Sadler, K., Abudari, G., Sweilem, A. S., Aldhari, M., & AlShammari, F. M. (2022). Quality of life

- assessment and supportive management in a cancer outpatient setting in Saudi Arabia. *Saudi Journal for Health Sciences*, 11(2), pp.131-138.
28. Koch, M., Hjermstad, M. J., Tomaszewski, K., Tomaszewska, I., Hornslien, K., Harle, A., ... & Koller, M. (2020). Gender effects on quality of life and symptom burden in patients with lung cancer: results from a prospective, cross-cultural, multi-center study. *Journal of thoracic disease*, 12(8), 4253-4261. doi: 10.21037/jtd-20-1054.
29. Oosterveld-Vlug, M. G., Custers, B., Hofstede, J., Donker, G. A., Rijken, P. M., Korevaar, J. C., & Francke, A. L. (2019). What are the essential elements of high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer. *BMC palliative care*, 18(1), 1-10.
30. Pidgeon, T., Johnson, C. E., Currow, D., Yates, P., Banfield, M., Lester, L., Allingham, S. F., Bird, S., & Eagar, K. (2016). A survey of patients' experience of pain and other symptoms while receiving care from palliative care services. *BMJ supportive & palliative care*, 6(3), 315-322.