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ORIGINAL ARTICLE

Caregivers' awareness and perception of palliative care at Najran University Hospital, Najran region, Saudi Arabia

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ABSTRACT

Background: The most terminally ill patients are cared for by their family members. This study aimed to explore caregivers' awareness of and perception toward palliative care.

Methods and Materials: This cross-sectional study was conducted at Najran University Hospital, Najran Region, Saudi Arabia, and focused on the 124 caregivers of terminally ill patients admitted to the hospital for palliative care or attending the outpatient palliative clinic during the study period. All participating caregivers provided information pertinent to this study using a pretested structured data collection instrument.

Results: Analyses revealed that 40 (32.3%) of the 124 caregivers comprising the study sample were unaware of palliative care prior to bringing their family member to the hospital. Respondents mostly sought information from healthcare providers (88, 71%) and the Internet (60, 48.4%). They primarily cited pain relief (48, 38.7%) as the main expectation from palliative care services. Moreover, 56 (45.2%) respondents were of the opinion that raising awareness was the main factor in the promotion of palliative care, and 48 (38.7%) respondents believed that health education about palliative care was inadequate.

Conclusion: Palliative care awareness of caregivers of terminally ill patients at Najran University Hospital is insufficient. Most of the participants emphasized the importance of public health education in promoting palliative care services.

Keywords: Caregivers, cultural awareness, health education, palliative care, perception, KSA, Najran.

Introduction

The perceptions of palliative care held by the families of patients suffering from fatal diseases can directly affect the progression of patients' condition and thus their quality of life [1,2]. Thus, improving the awareness of the benefits and limitations of palliative care is essential for increasing its acceptance by both the patients and their families [3]. Therefore, it is crucial to assess the beliefs regarding palliative care held by the terminally ill patients' caregivers [4].

This issue has been a subject of extensive research, and the available evidence indicates that both patients and their caregivers associate palliative care with death and despair. However, many are also of view that it increases comfort for patients at the end of their life, even though it is usually stigmatized in the society [5]. Similarly, Braithwaite et al. [6] found that cystic fibrosis patients and their families do not understand palliative care. A recent American national study showed that more than half of the caregivers of terminally ill patients have never heard of palliative care, while others tended to equate it with hospice care [7].

As palliative care tends to be stigmatized in Saudi Arabia [8], caregivers' awareness of palliative care services has not been previously explored in this context. This gap in extant research has motivated the present study, focusing on caregivers of terminally ill patients attending Najran University Hospital, Najran region, Saudi Arabia. The

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study results are expected to benefit health policymakers in Saudi Arabia aiming to increase caregivers' awareness of palliative care services and their aims.

Materials and Methods

The present cross-sectional study was conducted at Najran University Hospital, Najran region, Saudi Arabia, and focused on the caregivers of terminally ill patients admitted to the hospital for palliative care or visiting outpatient palliative clinic during the study period (from 1 August 2019 to 31 October 2019). Only adult caregivers (i.e., those aged 18 years and above) who provided care for the patient for at least 1 month were invited to complete a questionnaire, prior to which they signed the written consent form. We used convenient sampling, resulting in a sample of 124 participants.

The questionnaire adopted in this study was based on the semi-structured interview protocol developed by McIlfatrick et al. [9] The first part of the questionnaire focused on the caregivers' socio-demographic characteristics (age, gender, educational level, job, and relationship to the patient), as well as patient's cancer type and the duration of follow-up with the palliative care unit. The subsequent three sections aimed to elicit (1) their knowledge and perceptions of palliative care; (2) their expectations and accessibility for palliative care service provision; and (3) their suggestions for future strategies to promote awareness of palliative care, as shown in Appendix 1.

The questionnaire was translated into Arabic by the researchers and was tested for clarity as a part of a pilot study involving 12 caregivers. Their feedback was used to improve the questionnaire layout and wording, but their responses were not analyzed as a part of the main study. To avoid inter-rater variability, one author administered the questionnaire to all participants in a private hospital room to maintain privacy.

Prior to commencing the data collection, ethical approval was obtained from the Najran University Research Committee and all participants provided written informed consent. Full confidentiality and anonymity were maintained throughout the study and the collected data were exclusively used for research purposes.

The questionnaire data were verified and coded manually before entering it into a personal computer for further analysis. There were no missing data. Using Statistical Package for the Social Sciences (version 23), descriptive statistics (i.e., frequencies and percentages) was calculated, allowing the findings to be tabulated and plotted. In addition, chi-squared test was conducted to determine the significance of differences in participants' responses with respect to the demographic variables, whereby $p < 0.05$ was considered statistically significant.

Results

All caregivers who attended the hospital with their terminally ill family members during the study period agreed to take part in the study. This resulted in a sample of 124 participants (60 male and 64 female), 72 (58.1%) of whom were less than 40 years old. Most caregivers (88, 71%) were the sons or daughters of patients with a terminal illness, with colon cancer being the most prevalent diagnosis (56, 45.2%). Furthermore, the socio-demographic characteristics of the participants are shown in Table 1.

During the interviews, 40 (32.3%) of the 124 caregivers indicated that they were unaware of palliative care prior to their family member's referral for such services, and 68 (54.8%) participants were of the opinion that palliative care could be provided both at home and in specialized facilities. Majority of the caregivers obtained information about palliative care from healthcare providers or via the Internet (71% and 48.4%, respectively), as shown in Table 2.

When asked about their expectations of palliative care for terminally ill patients, 48 (38.7%) caregivers cited analgesia and symptomatic treatment, and 36 (29%) indicated monitoring of terminally ill patients' condition,

Table 1. *Personal characteristics of the study sample (n = 124).*

Caregivers' Personal Characteristics	***n***	**%**
Age group		
< 40 years	52	41.9
40+ years	72	58.1
Gender		
Male	60	48.4
Female	64	51.6
Educational attainment		
Secondary school	36	29.0
University degree	88	71.0
Employment status		
Housewife/Unemployed	20	16.1
Employed	88	71.0
Retired	16	12.9
Relation to the patient receiving palliative care		
Son/daughter	8	6.5
Sibling	20	16.1
Parent	88	71.0
Spouse	8	6.5
Location of primary cancer		
Colon	56	45.2
Breast	36	29.0
Lung	12	9.7
Brain	8	6.5
Other	12	9.7
Duration of received palliative care		
< 1 year	68	54.8
≥ 1 year	56	45.2

Table 2. *Caregivers' general knowledge about palliative care for terminally ill patients.*

Knowledge items	*n*	%
Caregiver was aware of palliative care prior to the hospital referral:		
Yes	84	67.7
No	40	32.3
Location at which the patient should receive palliative care:		
At home	24	19.4
At a specialized facility	32	25.8
Both at home and at a specialized facility	68	54.8
Sources of sought knowledge about palliative care: (participants were allowed to select more than one answer)		
Healthcare providers	88	71.0
Internet	60	48.4

Table 3. *Caregivers' opinions regarding factors that can inhibit palliative care promotion (participants were allowed to select more than one answer).*

Inhibiting factors	*n*	%
Lack of health education	48	38.7
Desperate patients/caregivers	20	16.1
Lack of specialized facilities for palliative care	16	12.9
Lack of palliative care services	12	9.7
Other factors	28	22.6

while only 28 (22.6%) and 12 (9.7%) noted supporting home care and providing health education, respectively (they were allowed to select more than one answer). It is also noteworthy that eight (6.5%) individuals did not have any expectations about palliative care services.

In the view of most caregivers (104%, 83.9%), palliative care services can be obtained at hospitals, while 23 (25.8%) believe that it can be delivered at home, and 8 (6.5%) stated that it could be obtained via the phone or the Internet (once again, they could select more than one answer).

Nearly half of the caregivers (56%, 45.2%) believe that raising awareness is the key factor in the promotion of palliative care, while 24 (19.4%) and 20 (16.1%) also cited increasing the accessibility of specialized facilities for palliative care and improving palliative care services, respectively. When asked what factors inhibit promotion of palliative care, 48 (38.7%) caregivers cited lack of health education about palliative care, as shown in Table 3.

Majority of the caregivers (92%, 74.2%) felt that providing health education about palliative care of terminally ill patients would result in a greater societal acceptance of this care type. In addition, 16 (12.9%) individuals suggested providing more specialized healthcare facilities and eight (6.5%) proposed improving communication between caregivers and healthcare providers (once again, they could select more than one answer).

Table 4 summarizes the findings related to the caregivers' awareness of palliative care according to their personal characteristics. It is evident that age, gender, employment status, and educational attainment do not affect caregivers' awareness about palliative care.

Discussion

In Saudi Arabia, it is expected that the cancer burden will grow by about tenfold by 2030 [10]. However, although palliative care provision is crucial for assisting terminally ill cancer patients and their families with coping with the disease [11], access to palliative care services in Saudi Arabia remains limited. This issue is mainly attributed to the lack of societal awareness about palliative care, limited caregivers' knowledge about these services, and inadequate community resources [12]. Therefore, the present study was conducted to explore the perceptions of caregivers of patients with fatal diseases toward palliative care.

The present study's findings showed that all caregivers of terminally ill patients were their family members and held a university degree. This is in line with the conclusions reached by Luijkx and Schols [13], who noted that taking the burden of care, specifically intensive palliative care in the end-of-life stage, requires the most caring, loving, and well-educated individuals. Similarly, Webster et al. [14] stated that, in developing countries, palliative care is mainly provided by the family members of terminally ill patients. Therefore, their empowerment through health education and training on the burdens of palliative care, as well as personal care, psycho-social support, and some medical care is highly important. In the present study, colon cancer was the main diagnosis of terminally ill patients, followed by breast and lung cancer, in accordance with the Saudi Cancer Registry [15]. It is important to emphasize that the high proportion of certain types of cancers among terminally ill patients in this study indicates their late presentation, when successful management is no longer possible. Therefore, public health education and early screening for these types of cancer should be made available.

Table 4. *Caregivers' awareness of palliative care based on their personal characteristics.*

Caregivers' personal characteristics	Aware		Not aware		*p value*
	n	%	*n*	%	
Age group					
<40 years	40	76.9	12	23.1	0.353
40+ years	44	61.1	28	38.9	
Gender					
Male	44	73.3	16	26.7	0.519
Female	40	62.5	24	37.5	
Educational attainment					
Secondary school	28	77.8	8	22.2	0.445
University degree	56	63.6	32	36.4	
Employment status					
Housewife/Unemployed	12	60.0	8	40.0	0.111
Employed	68	77.3	20	22.7	
Retired	4	25.0	12	75.0	
Relation to the terminally ill patient					
Son/daughter	0	0.0	8	100.0	0.091
Sibling	16	80.0	4	20.0	
Parent	60	68.2	28	31.8	
Spouse	8	100.0	0	0.0	
Location of primary cancer					
Colon	44	78.6	12	21.4	0.632
Breast	24	66.7	12	33.3	
Lung	8	66.7	4	33.3	
Brain	4	50.0	4	50.0	
Other	4	33.3	8	66.7	
Duration of received palliative care					
< 1 year	44	64.7	24	35.3	0.690
> 1 year	40	71.4	16	28.6	

The results reported in this work revealed that almost one-third of the caregivers of terminally ill patients were unaware of the availability of palliative care services prior to their family member's referral to the hospital. For majority of the participants, healthcare providers and the internet were the main sources of information. Similarly, a large-scale survey of community-dwelling adults conducted by McIlfatrick et al. [16] revealed that over 70% of the respondents had low to no knowledge of palliative care services. Authors of some other studies cited the caregivers' lack of knowledge about these services as one of the factors contributing to their underutilization [17,18]. For example, Alshammary et al. [10] reported that although most Saudis are concerned about cancer, they have limited knowledge about cancer-related pain and have several misconceptions about using opioids for pain relief as a part of palliative care. The authors also reported that over two-thirds of the participants in their study were of the opinion that palliative care could be provided in hospitals, while only 2.6% felt that it should be provided at home. On the other hand, Luijkx and Schols [13] noted that most people prefer to die in their homes, as being in a safe environment is particularly important for terminally ill patients [19]. As continuing everyday life with relatives and friends is even more important during the last days of life [20], many terminally ill patients prefer being cared for at home, rather than being hospitalized or placed into a specialized facility. However, most are eager to lower the burden (whether practical or financial) on their family members [20-22], and wish to stay in control of their own life and healthcare [23]. For those being cared for at home, feeling safe is also of great importance [24].

The caregivers that took part in this study expected palliative care services to mainly provide pain relief and symptomatic treatment to terminally ill patients, while also supporting those providing home care and providing them with relevant health education. Zeinah et al. [25] emphasized that caregivers that are more knowledgeable about palliative care tend to provide a better quality of life to terminally ill patients, as they are more aware of their need for pain relief and symptomatic management. Clark [26] similarly noted that enhancing end-of-life experience by managing patients' symptoms and providing pertinent information to the caregivers is an important component of palliative care, the main aim of which is to meet their individual needs and respect their end-of-life choices.

Caregivers who took part in the present study also felt that raising societal awareness of palliative care is essential in the promotion of this service, followed by increasing patients' access to the facilities for the provision of palliative care and improving palliative care services. On the other hand, they were of the opinion that lack of health education about palliative care was the key factor inhibiting the public awareness of palliative care, even though some caregivers also cited desperate condition of terminally ill patients and their caregivers, lack of specialized healthcare facilities, and inability to access palliative care services. These findings are in line with those reported by Lane et al. [27] who stated that strategies aiming to support the promotion of palliative care should focus on raising awareness of terminally ill patients and their caregivers to ensure that all terminally ill patients have access to high-quality care of their choice. Moreover, measures should be taken to reduce avoidance due to misperceptions or stigma, which can be achieved through public awareness campaigns or hospital-based and specialty-wide initiatives. Docherty et al. [28] noted that both caregivers and terminally ill patients go through four stages, denial, second-guessing, despair, and bereavement, as they try to come to terms with this condition. Therefore, healthcare professionals must manage each stage accordingly. The caregivers in this study suggested that, in order to provide more health education about palliative care of terminally ill patients, it is necessary to improve communication between caregivers and healthcare providers. Palliative care promotion strategies were examined previously, and their findings indicate that both caregivers and terminally ill patients would like better management of physical and psychological symptoms, such as pain and distress, which would require physicians to develop better listening skills [29,30].

The research results reported here further indicate that caregivers' personal characteristics did not affect their awareness of palliative care. Thus, when conducting widespread public awareness campaigns, it would be beneficial to tailor the message to different levels of education and age, as this may reduce misperceptions and thus improve the outcomes of such initiatives.

Recommendations

The Ministry of Health should implement strategies to raise caregivers' awareness of palliative care when a patient is first diagnosed with a life-threatening illness. It is also essential that healthcare professionals maintain open and honest communications with the caregivers of terminally ill patients. Most importantly, screening services must be improved, as early cancer diagnosis, especially for colon, breast, and lung cancer, can have a marked effect on disease progression.

Study limitations

Because the palliative care unit in Najran province is very modern, and Najran University Hospital is the only hospital in the region that provides palliative care. This study was the first of this kind in this region. Thus, even though no comparisons with other centers were possible, the results can be generalized to the entire region, since the university hospital receives referrals from the remaining hospitals serving this population.

Conflict of interest

The authors declare no conflict of interest regarding this study.

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Consent to participate

Written consent was obtained from all the participants.

Ethical approval

Prior ethical approval obtained from Najran University Research Committee date: COM-41-701.

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Appendix 1. *Interview guide.*

Caregivers’ general knowledge of palliative care

- Were you aware about palliative care before your family member was referred to this hospital for such services?
  - Yes
  - No

- Where do you think palliative care takes place?
  - At home
  - At specialized facilities
  - Both at home and at specialized facilities
  - I do not know

- If you needed information about palliative care, where would you look for it, or whom would you ask? (participants were allowed select more than one answer)
  - Healthcare providers
  - Internet
  - Friends
  - Other, please specify

Expectations

- What care would you expect palliative care services to deliver? (participants were allowed select more than one answer)
  - Provide analgesia and symptomatic treatment
  - Follow-up of terminally ill patients’ condition
  - Supporting home care
  - Health education
  - I expect nothing from palliative services
  - Other, please specify

Accessibility

- Where do you think patients receive these services? (participants were allowed select more than one answer)
  - At hospitals
  - At home
  - Via the phone or the internet
  - Other, please specify

Future strategies

- What factors would in your view promote public awareness of palliative care? (participants were allowed select more than one answer)
  - Increasing specialized facilities for palliative care
  - Greater promotion of palliative care
  - Improvements in palliative care provided
  - Other, please specify

- What factors would in your opinion hinder the promotion of public awareness of palliative care? (participants were allowed select more than one answer)
  - Lack of health education
  - Desperate patients/caregivers
  - Lack of specialized facilities for palliative care
  - Lack of palliative care services
  - Other, please specify

- What could be done to promote greater openness in discussion (and to inform future strategies)? (participants were allowed select more than one answer)
  - Improving communication between caregivers and healthcare providers
  - Providing health education about palliative care of terminally ill patients
  - Providing more specialized healthcare facilities
  - Other, please specify