

KNOWLEDGE OF PALLIATIVE CARE AND PREFERENCE OF END OF LIFE CARE A CROSS-SECTIONAL SURVEY OF PATIENT AND HOME CAREGIVER IN RIYADH

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Keywords:

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Knowledge,
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Abstract

Background:

Palliative care (PC) is a specialist medical care that is provided to patients with severe illness regardless of their diagnosis to alleviate symptoms and stress. Awareness regarding PC and end-of-life (EOL) is necessary to initiate the necessary care to the patients promptly and properly. However, knowledge and awareness regarding PC are insufficient among the population.

Aim:

To identify the knowledge of PC and associated factors among patients and their caregivers in Riyadh.

Methods:

This cross-sectional research was conducted on patients and their caregivers in National Guard Hospital, King Faisal Specialist Hospital, and King Fahad Medical City in the period from-----to----- . The study was conducted using a survey that investigated the demographics and knowledge of the participants.

Results:

A total of 220 subjects participated in this research, and 45.5% had awareness before admission of patients to PC. There, 50.9% of the subjects reported home and specialized centers where PC is provided, and 83.2% reported healthcare providers as the source of their information. The knowledge was significantly varied with employment status ($P=0.004$), relation to the patient ($P=0.003$), PC duration ($P=0.01$), tumor location ($P=0.002$), and perspective of subjects regarding the place of PC provision ($P=0.0001$).

Conclusion:

There was low knowledge regarding PC and a preference for EOL. The knowledge of the participants varied with several factors, including employment status, relationship to the patient, duration of PC, and tumor location.

Introduction

Palliative care, according to definition by the Center to Advance Palliative Care (CAPC), refers to specialist medical treatment that aims to alleviate the symptoms and stress experienced by those with severe diseases, regardless of their diagnosis. The objective is to enhance the overall well-being of both the patient and their family. Palliative care is administered by a multidisciplinary team of physicians, nurses, and other specialized professionals who collaborate with a patient's primary care physicians to provide supplementary assistance. It is suitable for individuals of all ages and at any point in a severe disease, and may be administered in conjunction with curative therapy [1]. The advantages include enhanced patient well-being, heightened patient and caregiver contentment, and reduced healthcare expenses [2].

Additionally, the scope of palliative care include end-of-life care and the facilitation of hospice transitions. Stow et al conducted a comprehensive study of the end-of-life care requirements of frail patients, revealing that these individuals had pain and mental suffering that was similar to that seen in patients with advanced cancer [3]. The task of predicting and determining the end-of-life stage might provide challenges in individuals who exhibit frailty [4]. Nevertheless, the electronic frailty index (eFI) has been used for the purpose of estimating 12-month mortality and has delineated three unique frailty trajectories that have potential utility [5]. Furthermore, it should be noted that the National Hospice and Palliative Care Organization (NHPCO) has released recommendations pertaining to the identification of unfavorable prognosis in chronic illnesses, which may also be extended to the context of frailty [6].

The authors propose that clinical indicators indicative of an unfavorable prognosis include recurrent trips to the emergency department or hospitalizations within a span of six months, a recent deterioration in functional capacity, and an inadvertent and gradual decrease in body weight exceeding 10% over the preceding six months. The aforementioned scenarios are likely to need an examination of a patient's objectives and the assessment of their eligibility for hospice care, while simultaneously addressing and managing the root cause. Hospice care is a Medicare benefit that is accessible to individuals in the latter stages of their lives, providing assistance for the physical, psychological, and existential anguish resulting from a disease. Similar to palliative care, this kind of care is delivered by multidisciplinary teams across several venues, with its major objective being the enhancement of quality of life for individuals with severe illnesses and their families [6]. In contrast to palliative care, this particular approach is restricted to individuals with a projected life expectancy of six months or fewer who have made the decision to decline life-prolonging interventions [7]. The provision of hospice care has been shown to be correlated with increased levels of patient and caregiver satisfaction, reduced use and expenditures of healthcare services, and a decreased probability of hospital-acquired mortality [8].

Study rationale

The existing body of literature pertaining to public awareness of palliative and end-of-life (EoL) care is relatively scarce. Only a small number of studies have been conducted in specific geographical areas, such as Ireland, Sweden, Italy, Australia, the United States, and Japan [9-12]. The majority of existing research indicate that there is a lack of sufficient awareness about palliative and end-of-life (EoL) care among the general community. Recent research done among the Saudi population have shown that Saudi respondents had little knowledge about palliative and end-of-life (EoL) care [13, 14].

Aim of the study

The study aims To examine the factors that may impact individuals' choice between opting for palliative care or end-of-life therapies.

Study objectives

- To investigate the level of knowledge of palliative care in Saudi Arabia.
- To investigate the preference towards end-of-life treatments in Saudi Arabia.
- To determine the factors associated with the preference of end of life treatments in Saudi Arabia.

Review of literature:

Tam et al. (2021) performed a cross-sectional questionnaire study. The research used a non-probability quota sampling technique to recruit individuals aged 18 and above residing in Macao over the period of July to September 2020. There were a total of 737 valid replies. The palliative care knowledge had an average accuracy rate ranging from 40.4% to 85.5%. In relation to end-of-life interventions, a majority of 62.0% of the participants opted for comfort care. Nevertheless, a significant majority of the participants expressed their agreement that the cessation of life-sustaining interventions should be avoided in all situations. The selection of comfort care over life-sustaining therapies was shown to be connected with respondents who exhibited greater levels of palliative care knowledge and had secondary and tertiary education. Furthermore, those who expressed agreement with the cessation of useless life-sustaining interventions were also shown to have a preference for comfort care [15].

Furthermore, Chenq et al. (2021) conducted a cross-sectional research in order to investigate the participants' understanding and perspectives on palliative care, as well as their preferences on end-of-life care, including considerations of the care location, site of death, truthfulness, and therapies at the end-of-life phase. A significant proportion of cancer patients (81.2%) shown a lack of familiarity with palliative care or its associated policies, whereas a minority (5.8%) demonstrated a moderate to complete comprehension of palliative care. A majority of the participants (75.3%) had favorable views towards palliative care. Regarding end-of-life care choices, the majority of cancer patients expressed a desire for receiving care in their own homes throughout the latter stages of their lives and to pass away in their own homes. 65.7% of cancer patients expressed a desire to get information on their diagnosis or prognosis, irrespective of the specific kind of cancer. A majority of the participants (54%) expressed a preference for enhancing their quality of life as opposed to extending their life expectancy. Over 33% of cancer patients expressed a preference for delegating the task of signing medical decision agreements to a family member or agency [16].

In order to evaluate the level of knowledge and attitudes pertaining to palliative care and end-of-life decision-making in the Eastern and Central provinces of Saudi Arabia, a cross-sectional research was done by Alsolami et al. (2023). The recruitment of participants was conducted via purposive sampling using social media. The data collection included several aspects, such as demographic information, knowledge pertaining to palliative care, attitudes towards palliative care, and the impact of cultural factors on end-of-life decision-making. The survey was completed by a total of 710 participants, with a response rate of 85%. The distribution of participants was balanced across genders, with a dominating age range of 25-54. More over 50% of the individuals were healthcare practitioners, with a significant number having over 15 years of experience in the healthcare field. A significant percentage of individuals had undergone formal training in palliative care and had direct participation in making choices related to end-of-life matters. Although the majority of participants exhibited a commendable comprehension of palliative care, there were still lingering gaps in knowledge, particularly pertaining to its timing. In general, the participants expressed a sense of comfort while engaging in conversations about end-of-life care and had a belief in the efficacy of palliative care. The impact of cultural factors on end-of-life choices was shown to be both advantageous and disadvantageous, since some individuals encountered cultural obstacles in the context of palliative care [17].

Furthermore, the study conducted by Baharoon et al. (2019) sought to examine the preferences for advance treatment among a cohort of Arab patients. The research observed a mean age of 48.7 years among the patients, with a standard deviation of 16.4. The study included a total of 104 individuals undergoing haemodialysis, including 73 diagnosed with advanced malignancy, 81 diagnosed with

chronic liver illness, and 35 diagnosed with chronic pulmonary disease. Over 80% of the participants expressed the belief that the physician should have the authority to choose the course of action for cardiopulmonary resuscitation. More than 60% expressed a desire to stay at home when their health worsened to the point of imminent death. None of the patients' end of life choice preferences showed any significant connections with religion, quality of life, illness duration, or other demographic variables [18].

Methods:

- **Study design:** Cross-sectional study.
- **Study population:** Saudi Arabian residents.
- **Study setting:** King Fahad Medical City
- **Study groups:** one group
- **Sample size:** 100 participants
- **Study Tools:** The recruitment of participants will be conducted via purposive sampling from social media platforms. The data collecting process will include several aspects, such as demographic data, knowledge pertaining to palliative care, attitudes towards palliative care, and the impact of cultural factors on end-of-life decision-making. The survey will consist of three distinct portions. The first segment of the study will gather sociodemographic information from participants, including variables such as age, gender, educational attainment, marital status, religious affiliation, employment status, occupation, and average monthly income within the previous year. The subsequent portion will center on the understanding of palliative care, inquiring with participants about their familiarity with the concept. The final portion will investigate the respondents' inclination towards EoL treatment choices.
- **Inclusion Criteria:** Saudi participants aged above eighteen and above, and are able to provide an informed consent and understand questionnaire content.
- **Exclusion Criteria:** Participants with severe auditory impairment, those who lack the ability to speak, and participants who may see their distress levels as impeding their capacity for informed consent and/or perceiving involvement as overwhelming.
- **Ethical consideration:** The research protocol will be granted approval by the review board. The research endeavor will adhere to the fundamental tenets of anonymity, privacy, and confidentiality. The participants will get a succinct summary of the study and its objectives.
- **Statistical Analysis:** The first step is the revision and coding of raw data using Microsoft Office Excel. Data processing and subsequent analysis in the research will be conducted using the Statistical Package for the Social Sciences. The gathered demographic data, knowledge level of palliative care, and attitude towards end-of-life (EoL) care will undergo descriptive analysis. Logistic regression models will be used to identify the characteristics associated with palliative care as the preferred type of end-of-life (EoL) care. These models will account for demographic covariates and the amount of awareness about palliative care. The estimated odds ratio (OR) and its corresponding 95% confidence intervals will be calculated. The statistical significance criterion will be established at $p = 0.05$.

Results:

A total of 220 participants were enrolled; the most dominant age group included those aged 45-55 years 61 (27.7%). Males were slightly dominant compared to females, 111 (50.5%) Vs. 109 (49.5%), respectively. Less than one-half of participants had a bachelor's degree 109 (49.5%), and more than one-half were employed 116 (52.7%). The large majority of subjects were healthcare providers 200 (90.9%), and being a parent 101 (45.9%) was the most reported relationship to the patient. The majority reported less than one year of palliative care 186 (84.5%), and the major location of tumor reported was colon 39 (17.7%); the demographics of the participants are revealed in table 1.

Table 1: Description of the studied sample

Variables	Description (n=220)
Age	
18-25	46 (20.9)
26-35	52 (23.6)
36-44	50 (22.7)
45-55	61 (27.7)
>55	11 (5)
Gender	
Male	111 (50.5)
Female	109 (49.5)
Education level	
Student	14 (6.4)
Basic	97 (44.1)
Bachelor	109 (49.5)
Employment status	
Employee	116 (52.7)
Not employee	104 (47.3)
Are you	
Healthcare Provider	200 (90.9)
Patient	20 (9.1)
Relationship to patient	
Parents	101 (45.9)
Siblings	8 (3.6)
Partner	17 (7.7)
Offsprings	79 (35.9)
Others	15 (6.8)
Duration of palliative care	
< 1 year	186 (84.5)
> 1 year	34 (15.5)
Tumor location	
Colon	39 (17.7)
Lung	29 (13.2)
Brain	25 (11.4)
Others	127 (57.7)

The knowledge and preferences of the participants were assessed through four questions; the questions and answers of the participants are illustrated in table 2. Less than one-half of the participants 100 (45.5%) were aware of palliative care before referring the patients. Both home and specialized centers were reported by 112 (50.9%) as the location where palliative care is provided. The majority, 183 (83.2%), stated that a healthcare provider would be the source of their information, and 182 (82.7%) thought that providing palliative care and symptom management is the service provided in such types of cases.

Table 2: Knowledge and preference of the participants

Questions and answers	Description (n=220)
Were you aware of palliative care before your family member was referred to this hospital for it?	
Yes	100 (45.5)
No	120 (54.5)
Where do you think palliative care is provided?	
At home	17 (7.7)
At specialized centers	69 (31.4)
Both	112 (50.9)
I don't know	22 (10)
If you need information about palliative care, where would you look for it, or who would you ask? You can choose more than one answer.	
Healthcare Provider	183 (83.2)
Friends	23 (10.5)
Internet	87 (39.5)
What kind of care do you expect palliative care services to provide? You can choose more than one answer.	
Providing palliative care and symptom management	182 (82.7)
Home care support	78 (35.5)
Health education	66 (30)
I do not expect anything from palliative services	12 (5.5)
Following up on the condition of terminally ill patients	130 (59.1)
The patient and his family need support, actual follow-up, and providing needs very quickly	6 (2.7)

The awareness of palliative care regarding the demographics of the participants is revealed in table 3. Awareness of palliative care is significantly associated with employment status ($P=0.004$) (Figure 1), relationship to the patients ($P=0.003$), duration of care ($P=0.01$) (Figure 2), and tumor location ($P=0.002$).

Table 3: Comparisons regarding Awareness of palliative care

Variables	Aware of palliative care		P value*
	Yes (n=100)	No (n=120)	
Age			
18-25	22 (22)	24 (20)	0.335
26-35	23 (23)	29 (24.2)	
36-44	19 (19)	31 (25.8)	
45-55	28 (28)	33 (27.5)	
>55	8 (8)	3 (2.5)	
Gender			
Male	50 (50)	61 (50.8)	0.902
Female	50 (50)	59 (49.2)	
Education level			
Student	5 (5)	9 (7.5)	0.051

Basic	53 (53)	44 (36.7)	
Bachelor	42 (42)	67 (55.8)	
Employment status			
Employee	42 (42)	74 (61.7)	0.004
Not employee	58 (58)	46 (38.3)	
Are you			
Healthcare Provider	95 (95)	105 (87.5)	0.054
Patient	5 (5)	15 (12.5)	
Relationship to patient			
Parents	35 (35)	66 (55)	0.003
Siblings	5 (5)	3 (2.5)	
Partner	14 (14)	3 (2.5)	
Offsprings	37 (37)	42 (35)	
Others	9 (9)	6 (5)	
Duration of palliative care			
< 1 year	91 (91)	95 (79.2)	0.016
> 1 year	9 (9)	25 (20.8)	
Tumor location			
Colon	15 (15)	24 (20)	0.002
Lung	9 (9)	20 (16.7)	
Brain	5 (5)	20 (16.7)	
Others	71 (71)	56 (46.7)	

***Chi-Square test**

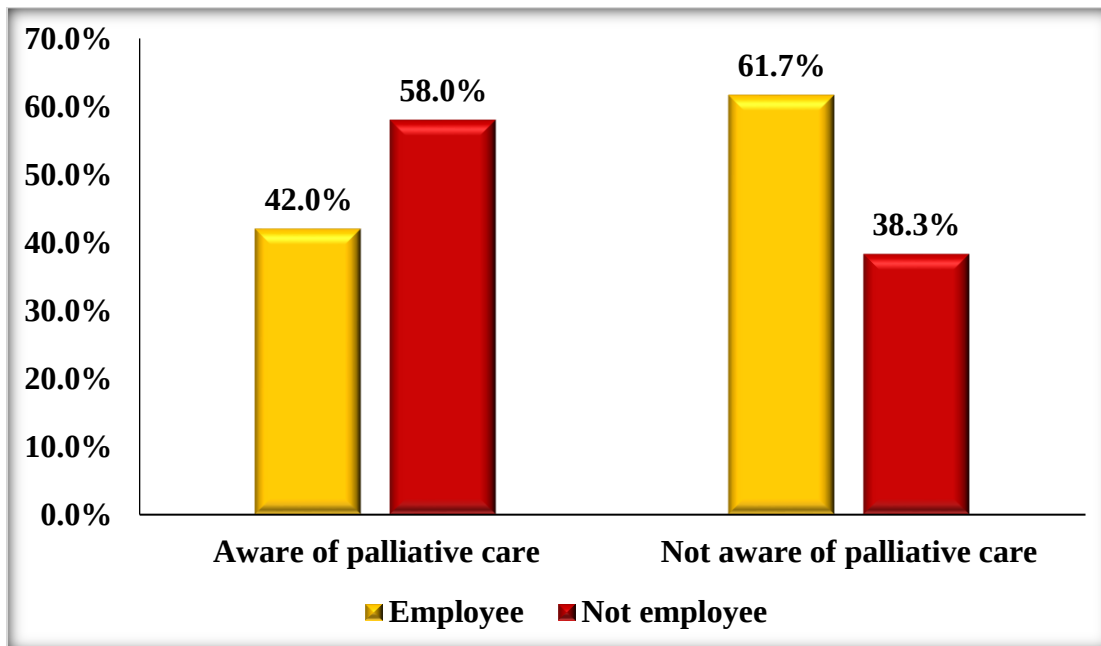


Fig 1: The awareness of participants regarding employment status

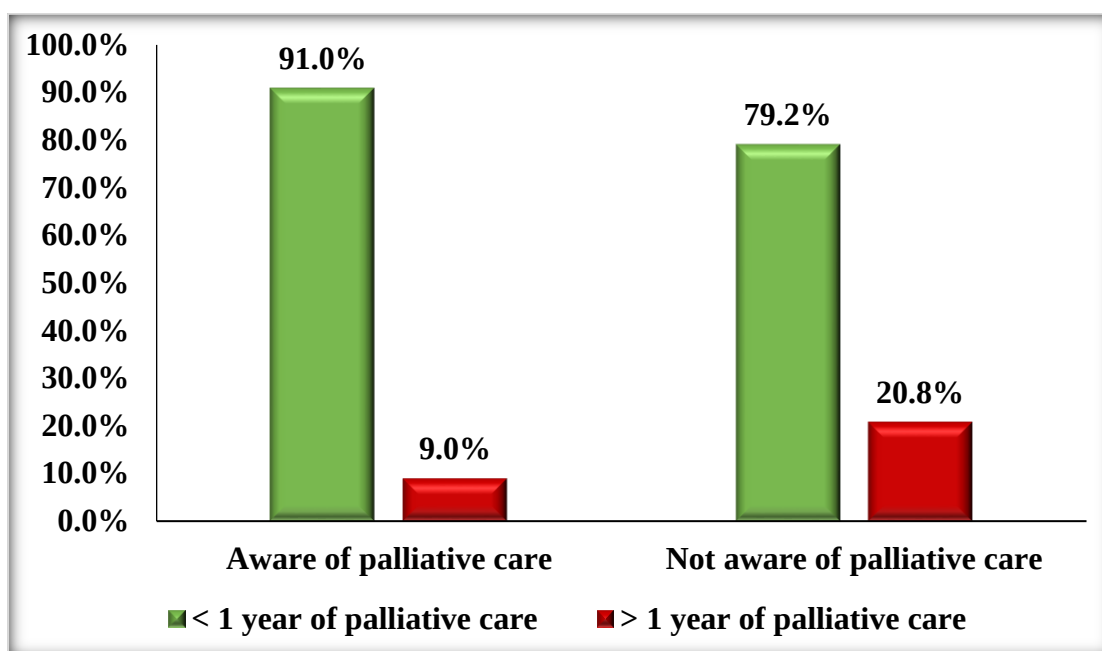


Fig 2: Awareness of participants regarding duration of care

The awareness of the participants varied with the thought of participants regarding the place of providing care ($P=0.0001$) and the kind of care provided by palliative care service based on the answers of participants, and it included health education ($P=0.039$), no expectation from palliative service ($P=0.001$) and supporting family and the patient with actual follow up ($P=0.03$), (Table 4).

Table 4: Awareness of the participants based on their preference

Questions and answers	Aware of palliative care		P value*
	Yes (n=100)	No (n=120)	
Where do you think palliative care is provided?			
At home	11 (11)	6 (5)	0.000
At specialized centers	40 (40)	29 (24.2)	
Both	49 (49)	63 (52.5)	
I don't know	0 (0)	22 (18.3)	
If you need information about palliative care, where would you look for it, or who would you ask? You can choose more than one answer.			
HCP	86 (86)	97 (80.8)	0.308
Friends	10 (10)	13 (10.8)	0.841
Internet	45 (45)	42 (35)	0.131
What kind of care do you expect palliative care services to provide? You can choose more than one answer			
Providing palliative care and symptom management	79 (79)	103 (85.8)	0.182
Home care support	32 (32)	46 (38.3)	0.328

Health education	23 (23)	43 (35.8)	0.039
I do not expect anything from palliative services	0 (0)	12 (10)	0.001
Following up on the condition of terminally ill patients	61 (61)	69 (57.5)	0.599
The patient and his family need support, actual follow-up, and providing needs very quickly	0 (0)	6 (5)	0.033

*Chi-Square test

Discussion:

Palliative care (PC) has several benefits, including relief of discomfort by early identification and management of illness and providing a network of support for the families of patients and caregivers [19]. However, the utilization of PCs isn't optimal, and this may be related to poor knowledge of PCs [20]. Therefore, this study was established to assess the knowledge of PC and preference for end-of-life (EOL) among patients and caregivers.

The primary caregiver is usually a family member who spends the most time with the patients, and they are involved in the day-to-day care of the patients [21]. In the present study, parents and offspring represented the majority of the participants. Additionally, the large majority of our participants were healthcare care providers, and this finding was in agreement with the findings of a study that enrolled individuals from the Eastern and Central provinces of Saudi Arabia that revealed that more than one-half of the participants were healthcare providers [17]. The current research discovered that the main location of the tumor was the colon, and the majority reported PC for less than one year. Similarly, in a previous Saudi study, the primary location of cancer was the colon (45.2%), and the duration of PC was less than one year, as reported by 54.8% [18].

The objective of PC is to improve the quality of life of patients with life-limiting disease and their caregivers by addressing spiritual, physical, and psychological needs [22]. In our research, we found that less than one-half of our subjects were aware of PC before the admission of patients to hospitals. However, a larger proportion knew the kind of service provided by PC symptom management. The findings in our study demonstrated a low level of knowledge. However, our findings were better compared to those reported in a previous study from Makkah that enrolled 378 family caregivers, and it was discovered that 73.8% of the participants were unaware of PC until their family members were admitted to the hospital. Additionally, the mean score of knowledge indicated limited knowledge regarding PC [19]. Our findings were inferior to those reported in another Saudi study; another study from Najran demonstrated that 32.3% of caregivers were unaware of PC [18].

EOL care at home for cancer patients is becoming more frequent due to the elevated frequency of patients who wish to die at home [23, 24]. In our research, almost one-half of the participants thought that PCs could be provided at home and at specialized centers, and healthcare providers were the most reported source of information. Similarly, in the study from Najran, both home and specialized facilities were commonly reported as the location for receiving PC (54.8%), and 71% reported healthcare providers as the source of information [18].

One Saudi study conducted on nursing students revealed poor knowledge regarding PC [25]. A study from Jordan also conducted on nurses in the intensive care unit found that the nurses had insufficient knowledge regarding PC [26]. Such findings indicate that even healthcare providers have low knowledge regarding PC.

The assessment of public awareness in one study revealed that 70% of the participants had low to no knowledge regarding PC services [27]. In Canada, the assessment of public awareness regarding PC declared that among 1518 adults, 45% only had the knowledge, and among this proportion, only 46% had actual knowledge [28]. In Egypt and among primary healthcare, only 6.7% of those providers had

good knowledge regarding PC [29]. Regardless of the population under investigation, all the previous findings reported lower knowledge and awareness regarding PC compared to our study.

The assessment of factors affecting awareness in our study included employment status, relationship to the patient, duration of PC, location of the tumor, the location where PC is provided, and kind of care provided by PC. Based on a previous Saudi study, age, relation to the patient, duration of PC, and employment status were considerably associated with the level of knowledge. The age of 26-35 years, students, being brother/sister, and PC duration of less than one year were associated with knowledge. On the other hand, gender, tumor site, and education level revealed no association with knowledge [19]. Such findings were in contrast to ours; our findings and the previous findings were in agreement regarding the association with relation to the patient, PC duration, employment status, and the lack of relation with gender and education level.

In Najran, awareness wasn't associated with any age, gender, education, employment, relationship to patients, location of cancer, or duration of PC [18]. This was in line with our findings regarding the absence of an association between awareness and age, gender, and education.

In Singapore, among patients and caregivers, the awareness of PC was significantly lower among patients (43%) compared to caregivers (53%) [30]. However, this correlation in our findings was non-significant ($P=0.054$). In Pakistan, one research declared that participants under 40 years considerably tended to have enhanced knowledge regarding PC [21]. Nonetheless, age didn't affect the knowledge of our participants.

PC and EOL care provides extensive multidisciplinary healthcare to the cases complaining of various life-shortening and life-threatening illnesses, including cancer. This care aims mainly to alleviate symptoms of deprivation, such as physical pain [31]. However, in our study, 12 (10%) reported that they didn't expect anything from palliative service; all such subjects significantly had no awareness.

Conclusion:

There was low knowledge regarding PC and a preference for EOL. The major source of information the participants sought was the healthcare provider. The knowledge of the participants varied with employment status, relationship to the patient, duration of PC, tumor location, and the perspective of subjects regarding the location of providing PC and the kind of service.

• Time plane

Task	Duration in months							
	Mar ch	Apr il	May	June	July	August	Sept ember	October
1. Proposal	*							
2. Ethical approval.		*						
3. Questionnaire pre-test			*					
4. Questionnaire			*					

5. Data collection				*	*				
6. Data entry									
7. Data analysis							*	*	
8. Report writing									*
9. First draft									*
10. Final report									*

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