This is an accepted article in press for IJMDC
The designed pdf version will be available soon
Title: Palliative Care Awareness, Knowledge and Attitude Among General Population and Health Care Workers in Jeddah, Saudi Arabia: A cross-sectional Study.

Running title: Palliative Care Awareness, Knowledge and Attitude Among General Population and Health Care Workers

Type: Original article

Authors:

Nabil A Almouaalamy 1,3,4, Lama I Sultan 2,3,4, Mohamed Khalid Mujalled 3,4, Abdulkareem A Alharthi 5, Ahmad H Alhouthali 3,4, Abdullah A filfilan 3,4

Affiliation:

1. Oncology Department. Princess Noorah Oncology Center, King Abdulaziz Medical City, National Guard Health Affairs, Jeddah, Saudi Arabia

2. Clinical Nutrition Department, Ministry of National Guard Health Affairs, King Abdulaziz Medical City, Jeddah, Saudi Arabia,

3. College of Medicine, King Saud bin Abdulaziz University for Health Sciences, Jeddah, Saudi Arabia.

4. King Abdullah International Medical Research Centre, Jeddah, Saudi Arabia.

5. Alsafer primary health care center, Ministry of Health, Jeddah, Saudi Arabia

*Corresponding Author:

Mohamed Khalid Mujalled

College of Medicine, King Saud bin Abdulaziz University for Health Sciences, Jeddah, Saudi Arabia. King Abdullah International Medical Research Centre, Jeddah, Saudi Arabia.

Email: mo_khaled@hotmail.com
Abstract:

**Background:** Palliative care (PC) aims to affirm life while regarding dying as a normal process, to provide support to enable patients to live as actively as possible until death, and to offer support to the family during the patient's illness and in their bereavement. It is an emerging medical specialty, but palliative care awareness varies widely according to international research to date.

**Methodology:** We conducted an observational descriptive cross-sectional study at King Abdulaziz Medical City (KAMC). The data included in the study was obtained from a paper-based questionnaire that will determine the knowledge and awareness regarding palliative care, the attitude toward palliative care, and experience towards palliative care. The statistical package for social sciences (SPSS, version 26) was used to analyze the data. Permission and approval for conducting this research are obtained from the ethical committee at King Abdullah International Medical Research Center (KAIMRC) and Institutional Review Board (IRB).

**Results:** We included 262 participants who fit our inclusion criteria 81% of the respondents of our study said they have heard about palliative care. When asked about the aim of PC, 92.4% said PC is for patients' comfort.

**Conclusion:** Knowledge and awareness of PC among the medical student and healthcare worker in Saudi Arabia is relatively high compared to the general population but will need more media involvement and increase the palliative care-related topic in the curriculum for healthcare specialties.

**Keywords:** Palliative care, palliative treatment, palliative therapy, palliative medicine, hospice care, comfort care
Introduction

The World Health Organization [1] has advocated palliative care as a public health issue: United Nations conventions acknowledge access to such care as a human right [2]. Palliative care (PC) aims to affirm life while regarding dying as a normal process, provide support to enable patients to live as actively as possible until death, and offer support to the family during the patient's illness and in their bereavement [3]. Though palliative care has been somewhat established in many developed countries globally, it is an emerging medical specialty in many developing ones with the establishment of palliative care centers in India, Saudi Arabia, and Lebanon [4,5,6]. Awareness of PC varies widely according to international research to date [7-10]. A telephone survey of 667 Irish adults [7] reported that many people were unfamiliar with the terms associated with palliative care and end of life. This low level of awareness may have implications for care, lead to negative impressions and impact on equitable access to services, resulting in negative consequences for the quality of care provided to the dying and bereaved [10-14]. Also, multiple studies show a lack of awareness regarding palliative care among health care workers; one research shows that nurses thought that PC is only for actively dying patients. Given that the world's population is aging, with a greater incidence of cancer and a higher prevalence of chronic conditions [17,18], the demand for high-quality hospice and palliative care services will undoubtedly increase. Historically there is a lack of understanding of the concept of palliative care, and little is known about the awareness of the availability among members of the general public and health workers as well [19-22]. This contrasts with the increasing profile of palliative care as a critical national and regional strategic priority area. It was one of the significant elements discussed in Saudi Arabia ministry of health plans toward the vision 2030.
To date, public awareness of palliative care and what strategies should be used to target awareness has received little attention from researchers. A detailed and comprehensive understanding of public views is needed to target education and policy campaigns and manage future needs, expectations, and end-of-life care resourcing. Thus this study aimed to explore general and health workers views towards palliative care and explore strategies to improve awareness.

**Subjects and methods:**

We conducted an observational descriptive cross-sectional study at King Abdulaziz Medical City (KAMC). The medical city is a tertiary care center located in the western province of Jeddah, Saudi Arabia. The data included in the study was obtained from a paper-based questionnaire. Written consent was taken to fill out the questionnaire if the participant agreed to participate. Our study targeted: general population, medical students, and healthcare workers. We included all adults above the age of 18 from all nationalities and both genders. The sampling technique was non-probability convenience sampling, The statistical package for social sciences (SPSS, version 26) was used for data analysis. Quantitative variables were analyzed by measuring the mean and standard deviation. On the other hand, qualitative variables are presented by frequencies and percentages. Bar graphs and box whisker plots were developed to demonstrate qualitative and quantitative variables, respectively. For inferential statistics, correlation analysis or t-test were done to compare quantitative variables, while the chi-square test was used for qualitative variables. Moreover, logistic regression analysis was performed to detect which item has a higher impact. P-values of <0.05 were considered significant for all two-tailed tests. The patients' data were collected by distributing a validated self-administered questionnaire to the general population, medical students and health care professionals. Our questionnaire had four sections: Section one:
in this section, the demographic data of our participants were obtained, which includes age, gender, nationality, educational level, occupation. Section two: Included questions to determine the knowledge and awareness regarding palliative care. Section three: We assessed the attitude about palliative care using a Likert scale where five represents strongly agree and one represents strongly disagree. Section four: Included questions to determine populations' experience towards palliative care. Permission and approval for conducting this research are obtained from the ethical committee at King Abdullah International Medical Research Center (KAIMRC) and Institutional Review Board (IRB).

**Results**

Demographics: Our study included a total sample size of 262 participants, 149 were males, and 113 were females as the participants’ ages varied from (below 20 – above 60), with ten years interval for each category. Since the knowledge is crucial here, the respondents' job was also addressed, according to our results, the majority 57.6% were medical students followed by the general population and health care professionals. The students were from the pre-final and final years as they would have possessed basic knowledge on these issues to understand their roles played in a palliative care setting. Regarding the level of education, participants having a diploma or high school education represented 51.9% of our respondents [Table 1].

Knowledge: Eighty-one percent of the respondents in our study said that they have heard about palliative care. When asked to describe their PC knowledge, 50.3% of the respondents scored six or above with ten excellent meaning knowledge and 0 poor meaning knowledge. The most
significant source of knowledge about PC was from working as a healthcare professional, accounting for 42% of the respondents, followed by university at 35.5% [Table 2]. When asked about PC's aim, 92.4% said PC is for patients' comfort, 90.5% answered "for pain relief," and only 67.9% responded that it tries to achieve Care service to homes/keeping the sick/elderly at home longer. Regarding who should receive palliative care, 90.8% answered that all terminal disease patients should receive PC. 90.5% said that cancer patients should receive PC. Only 57.6 said that all heart disease patients should receive PC. Participants were also asked about the location of the PC. The majority, 88.5%, answered "at the hospital. Other answers are shown in [Table 3].

Also, the respondents were asked about the components of the palliative care team. The responses to the eight answers are shown in [Table 4] 36.3% of the respondents believe that palliative care should be available to all patients, 35.5% said that it should be available to those who require the service, and 26% thought it should be open to the patient when the disease becomes terminal. Only 2.3% said that it should not be available to any patient.

Behaviors: Our data included a total of 13 questions exploring the behavior of participants toward PC. The included questions were meant to explore various aspects from access to palliative care, PC's role to the target population of palliative care. The participants were given five options on Likert scale for each statement; strongly agree, agree, neutral, disagree, and strongly disagree. However, the responses to behavior statements are shown in [Table 5].
Discussion: The idea of palliative care (PC) was first introduced in Saudi Arabia in 1992, after which the other Middle Eastern countries started to follow [23]. However, since the time PC was introduced, very few articles focused on this subject, particularly on the general Saudi public's awareness, perception, and attitude toward PC.

Knowledge: Awareness and perception of Palliative Care (PC) among the participants seems to be adequate. Around 81% of our sample have heard about palliative care, while the remaining did not know about it. Contrasting our results, a public survey study was done in Saudi Arabia and found that the public knowledge of PC was as low as 16.2%, which was significantly lower compared to the public awareness of PC found in Sweden 59%, Japan 63.1%, and even Italy 23.5% [23] [28]. The respondents were asked to describe their level of knowledge on a scale of 1 to 10, 1 being poor knowledge, and 10 is Excellent knowledge. A score of 3 or less is labeled as "poor," and a score from 4-7 is labeled as "good" above seven is excellent. 29.7% have poor knowledge, 45.4% have good knowledge, whereas 24.8% claimed that they have excellent knowledge. Upon further classification based on the cumulative percentages, we can understand that at 5 the cumulative percent is around 50 percent which shows around 50% of the respondents are not well aware of the concept of palliative care while around 50% are well aware and they rated above 5 which depicts toward a better level of knowledge regarding the palliative care. However, in the Saudi public Survey, they found that the level of awareness of PC was only 2.0% respondents who have a clear idea of PC, 11.2% have a reasonable idea of PC, 9.0% have a vague idea, and 14 0.7% only knew it by name. The majority of the respondents, 77.2% Never heard of PC. [23]
Upon asking "From where have you heard PC", 35.1% of the participants have heard of the PC through university and Health education material, and 42.0% through Working in health/hospital/community services while only 13.4% via media. This is understandable as the topic of PC is not attractive to be offered in the media for the general population. Surprisingly, in a study, 78% of the respondents reported no awareness of PC, and the most common sources of information reported were the media, close friends, or relatives receiving PC. [24] We believe variation in responses is because most of the participants of our study are affiliated with medical students and healthcare professionals, while in the Swedish study, it was from the general population. In Westerlund C et.al study, participants were asked what they considered the aims of PC, by choosing all relevant responses from a list of 19 options. More than half of the responses were; "end of life care", "pain relief", "dignity," and "peaceful death" [24]. That was persistent with our results, which showed that 92.4% of the participants think "comfort for patients," and about 90.5% for pain relief, 78.6% dignity in death. While 16.8% do not know what is the main aim of palliative care. Contrasting our results, Benini F et al. findings showed that only 38.7% of their participants believe that PC aims to improve the quality of life of sick people, and 23.1% said it is only reassurance for the patients [25]. This variation is owed to the population's selection, as we included more participants of medical students and healthcare workers. When asked, "what PC consists of " with 12 options to choose from, more than one can be selected. 84.7% of the responses picked control of pain and other symptoms at home, 75.2% said medical care in a hospice, and 61.5% of the participants think that PC should include someone to talk to about spiritual matters. While only 10.9% of the Benini F et al. survey said that Religious support should be part of the PC, 71.5% answered reduce physical suffering, and 40.4% said Special medical assistance around the clock [25]. We believe that this variation in response to spiritual matters is
a reflection of religious and cultural differences. WHO defines palliative care as for all life-threatening diseases, so the next question asked, "who should be receiving PC" 90.8% and 90.5% of the participants picked "all terminal diseases" and "cancer," respectively. While 57.3% of the participants said that patients with kidney failure should receive palliative care. Similarly, in an Indian study, 89.8% and 59.7% of the responses were "metastatic cancer diseases" and "all dying patients," respectively, and around 60% picked "chronic kidney disease (CKD) on dialysis " [25]. Meanwhile, 32.6% of the Saudi public survey participants do not know when people should receive PC, while 29% think the PC is offered when there is no more treatment available [23]. It appears that the location of the receiving PC is known to most of our responders. When we asked to choose from a list of options, more than one can be picked, a majority picked "at hospital" where palliative care should take place 88.5%, followed by option "at hospice" representing 82% of the responses. In the Westerlund C et al. report, a majority endorsed the person's own home as the preferred site for receiving PC 68% [24]. Similarly, Alkhudairi HM's findings showed 40.3% of respondents do not know where patients should receive PC, whereas 727 36.6% believe that patients should receive PC in the hospital. [23] Question number 14 of the questionnaire consisted of "who are the palliative team members." 96% of the respondents believe that palliative care consultants are members of the palliative team. And 80.5% said oncologists while 96.6% said palliative care nurses. On the other hand, in the Nigerian study, when they were asked about "the members of the palliative care team by" out of 96 respondents, the majority picked "Nurses," "Physicians," Physiotherapists" and their percentages were 95.8%, 94.6%, 87.5% respectively [26]. The timing of initiation PC treatment is as crucial as the treatment itself, so we asked our responders in question 15, "when should information on palliative care be provided?" 36.6% answered it should always be available to all the patients. Meanwhile, 26% think that PC should
be offered only when the illness becomes terminal. Compared to the Saudi public survey [23], around 32.6% of the respondents do not know when people should start receiving PC, while 29.1% think that PC is offered when there is no more treatment available.

Attitudes and behavior towards palliative care: Although there is a strong restriction by the Saudi government on the sale and use of opioids outside the hospital, about 51% of participants strongly agreed with the statement that "everybody who needs and wants palliative care should be able to access it." Moreover, a low number of doctors specializing in PC and fellowship in PC have recently started in Saudi Arabia with the Saudi Commission for Health Specialties [8]. We believe that this question has not been raised before in the Middle East, reflecting the lack of research on palliative care in the area.

**Conclusion**

Knowledge and awareness of PC among the medical student and healthcare worker in Saudi Arabia is quite high compared to the normal population. Thus, there is a need for more institutional efforts by implementing educational programs focusing on the general population using all multimedia to advertise and promote this growing branch of medicine that will functionally take care of terminally ill patients and promote literacy of PC among its populace. There is also a need to conduct a nation-wide similar survey to confirm our results. The participation of non-governmental sectors should also take place in these programs to improve the general public's knowledge and awareness regarding PC. The authors recommend to: Encourage more media usage to increase awareness about palliative care; Increase the palliative care-related topic in the curriculum for healthcare specialties

**List of Abbreviations:**
Conflict of Interests:
The authors declare that there is no conflict of interest regarding the publication of this article.

Funding:
None

Consent for participation:
informed consent was obtained from all the participants

Ethical Approval:
Please provide in the following format: Ethical approval was granted by Ethics Committee/Institutional Review Board/Research Committee (choose whichever is applicable) via reference/letter number ---- dated: -----.
References:


https://doi.org/10.4081/nursrep.2011.e8

https://doi.org/10.1136/bmj.c4860

https://doi.org/10.1186/1472-684X-9-4


https://doi.org/10.4103/0973-1075.125547


https://doi.org/10.1177/0269216310368578


