

# Perceptions and Attitudes towards the Concept and Approach of Palliative Care among Caregiver's of Patients on End-of-Life Care: A Cross-sectional Survey

Sameena Shah (✉ [shahsameena4@yahoo.com](mailto:shahsameena4@yahoo.com))

Vancouver Island Health Authority

Faizan Qaisar

Ali Medicare

Iqbal Azam

Aga Khan University

Khairunnisa Mansoor

Aga Khan University Hospital

---

## Research article

**Keywords:** Palliative Care, Care giver's, Understanding, Attitudes, incurable disease

**Posted Date:** January 6th, 2020

**DOI:** <https://doi.org/10.21203/rs.2.16031/v2>

**License:** © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License. [Read Full License](#)

---

## Abstract

**BACKGROUND** As care-giver's play an integral role for patients as disease progresses, it is necessary to assess their knowledge and understanding of palliative care to ensure meaningful uptake before developing an appropriate palliative care program. **METHODS** A cross-sectional survey was conducted. Data was collected from the Aga Khan University Hospital in-patient and out-patient departments and home-based palliative care services from mid 2015 to 2016. All adult care-giver's who met the inclusion criteria and consented completed a questionnaire till the sample size was reached. Univariate and multivariable analysis and results were reported as crude prevalence's, crude and adjusted prevalence ratios with 95% confidence intervals using Cox-proportional hazard algorithm. Mean difference of knowledge and attitude scores by care-giver variables was assessed using one-way ANOVA. SPSS version 18 was used and a p-value of less than 5 percent was treated as significant. **RESULTS** Out of 250 care givers more than 60% were 40 years or less and the majority were males and at least graduates. Approximately 70% of the respondents agreed with the opinion that the person suffering from cancer should be informed about the diagnosis and disease progression. About forty five percent (95% C.I.: 39.03%, 51.37%) of the study respondents had enhanced understanding about palliative care. Individuals aged <40 years, with an education level of Grade 10, children or relations of the patient were found to have significantly more knowledge and understanding about palliative care. The majority believed that the patient should be informed about the diagnosis and should be facilitated to carry out routine activities and fulfill wishes. **CONCLUSION** Nearly half of care giver's of patients affected by incurable conditions have enhanced understanding of the PC approach. Two foundational aspects showed a consistently enhanced understanding across age groups, gender, education level, and relationship with the patient. Firstly, that palliative care should be offered to everyone suffering from an incurable disease and, secondly, that this approach encompasses not just physical, but also psychological and social needs of the patient and the family. These findings should help inform the establishment of a palliative care program that fills the gaps in knowledge and understanding of this beneficial approach in care givers.

## Background

The World Health Organization (WHO) defines palliative care (PC) as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. [1] Palliative care is a comprehensive patient and family-oriented approach that not only provides care for physical symptoms but also identifies and addresses the psychological, social and spiritual needs of the patient. Furthermore, this approach extends to include the family members not just during life, but also after the death of the patient. The palliative care approach, given its holistic nature, is multi-disciplinary and is based on a team that includes physicians, nurses, social workers and many other allied health care workers. In addition, family members take on an increasingly integral role as care-giver's as disease progresses. The team addresses and prioritises the patient's needs pertaining to physical, emotional, social, and spiritual dimensions of palliative care on a continuum while coordinating this care with all concerned as needed.[2] Palliative care includes the prevention and reduction of suffering by early identification, assessment, and treatment of physical, psychosocial, and spiritual aspects of serious illness and injury.[3]

The benefits of integrating palliative care at a public health level on quality of life and on symptom control are well established internationally.[4, 5]

By 2060, 83% of deaths worldwide due to health related suffering will occur in low-income and middle-income countries which constitute about 47 % of the world population.[6] Cancer is the second leading cause of death globally and 70% of them occur in low and middle income countries like Pakistan.[6]. By 2020, the WHO estimates that globally, more than 15 million people will experience cancer, and 10 million will die of it each year, which amounts to a 60% increase in deaths.[7,8]

An ongoing study that is monitoring the development of palliative care services globally and aims to categorize countries to levels of palliative care development, placed Pakistan in category 3a (Isolated palliative care provision) in 2017. It also notes that 47.5% of the world's population belongs to countries that fall within this category.[9] In Pakistan, there are only a handful of medical institutes that offer palliative care.[10] Given these circumstances, there is a great need to develop and integrate

palliative care into health systems at a public health level. Among several challenges to developing a public health approach, one is the paucity of public awareness of palliative care, as demonstrated by numerous international surveys.[11,12,13,14] Moreover, the understanding of the situation is complicated by the limited research in this relatively new field in Pakistan. [10,15,16]

For any palliative care program to succeed, it should be available to all those who would benefit from it.[17] Lack of understanding of the concept and scope of PC and misconceptions are a barrier to the uptake and meaningful utilisation of this comprehensive approach by patients and families.[4,13,18]<sup>12</sup> This compounds the stress and burden of the family members caring for the terminally ill patient or informal caregiver/s, who may lack training, experience or preparation for this challenging and emotionally draining task. To ensure meaningful and successful uptake, potential care giver's, whether family members or professional, need to have knowledge and understanding of the benefits of this approach in the care of their patient. [4,5,17,19,20,21] The objectives of this study, therefore, were to determine the perceptions, knowledge and attitudes of care giver's of patients who had been diagnosed with incurable conditions about the concept and principles of PC. The findings will help to inform interventions to enhance knowledge and address misperceptions as palliative care becomes more widely available in the country. Misperceptions are common in the public and caregivers and can adversely impact the uptake of this beneficial service even where it is available.[21]

For purposes of clarity, the caregiver/s, were defined as a person/s who gives help and protection to someone such as a child, an old person, or someone who is sick.[22] The primary care giver is usually the family member who spends the most time with the patient and is involved in the day to day care of the patient. However, there may be other paid care givers who would also be in communication with the physicians and nurses and involved in making decisions about patient care.

In the context of palliative care and Pakistan also, this would be any individual who spends time with the patient, may be involved in feeding, dressing, or cleaning the patient, and making day to day decisions on behalf of the patient. This person may also be involved in discussing patient condition or disease progress with the medical team or distant family members. In our socio-cultural system, this is usually one or more close family member/s like, the spouse, son/s, daughter/s, brother/s and or sister/s. However, occasionally, this individual may be a trained attendant, nurse or nursing assistant.

## Methods

A cross-sectional survey was conducted over a period of one year on (n=250) primary care-giver/s to assess their perceptions and opinions of palliative care and attitudes towards it after obtaining approval from the Ethics Research Committee of the Aga Khan University Hospital (AKUH). This sample size estimate was based on knowledge of Palliative Care (PC) anticipated as 50% with level of significance of 5%, precision of 6.5% and incompleteness or refusal of the questionnaire of 10%. The study participants were recruited from the in-patient cancer, neurology, pulmonary and cardiac wards, outpatient consultant clinics, and patient's homes during home visits. The inclusion criteria were any person (female or male) over the age of 18 years who was taking care of a patient suffering from an incurable disease or condition including cancer, was aware of the diagnosis and the prognosis, and who conformed to the operational definition of care giver, and who gave informed consent. All care givers who were less than 18 years of age, who refused consent, or did not conform to the operational definition of the primary care giver/s were excluded from the sample. A questionnaire was developed in both Urdu and English and was validated and cross validated and piloted on a sample drawn from the same study population meeting the same inclusion and exclusion criteria, before being used for data collection. To ensure face and content validity, the questionnaire was developed after reviewing several papers assessing knowledge, beliefs and attitudes about PC. It was ensured that it was relevant to the Pakistani context and setting. Some of the questions were generic in terms of the meaning and principles of PC whereas others were regarding attitudes towards core concepts of PC. A section covering demographic and social aspects like age, gender, educational qualifications, and relationship with the patient was included. The questionnaire was then reviewed by the statistician. A few modifications were made after it was piloted. The final questionnaire was in both Urdu and English and each respondent was free to select the language of choice. All study participants were approached by the nursing staff or the home-based family physician in the selected study sites; all those who met the inclusion criteria and gave informed consent were asked to complete the

questionnaire themselves till the sample size was reached. All the participants were able to read and write in at least one language. The data was collected anonymously with access to the principal investigator only.

## Data Analysis

The data was double entered by two data entry operators in Epidata, then verified for data entry errors and cleaned. The cleaned data was then converted into SPSS for analysis. Frequency distributions of care takers' age, gender, level of education, relationship with the patient, opinion about whether the person receiving palliative care should be allowed to carry out normal routine activities or to fulfill all his/her wishes and whether a person should be given a diagnosis of cancer or disease progression were generated.

We looked at several outcomes. One was binary for which we have reported prevalence ratios with 95% CI. Then we derived scores made from correct answers from each component and then compared these with demographic variables. Prevalence with 95% confidence interval for knowledge of palliative care was calculated. The association of knowledge of palliative care with care taker's age, gender, level of education and relationship with the patient was assessed using univariate and multivariable analysis and results were reported as crude prevalence's, crude and adjusted prevalence ratios with 95% confidence intervals using Cox-proportional hazard algorithm. Each question related to opinion and attitude was given a score of 1 when positive otherwise a score of zero was given. These scores were then aggregated to obtain final correct knowledge and attitude scores for different aspects of PC, including 'goals of PC' score, 'focus of PC' score, 'composition of PC team' score, 'setting of PC' score, 'knowledge about hospice' score, opinion about 'provider of PC' score, opinion about needs of patients suffering from a terminal disease or incurable disease' score, opinion about whether PC should be offered to people diagnosed with a terminal or incurable disease score, opinion about 'the best setting to provide PC' score and opinion about 'the best source for obtaining knowledge about PC' score. Mean difference of these scores by primary care giver's age group, gender, education level and relationship with the patient was assessed using one-way ANOVA. SPSS version 18 was used to analyze the data. A p-value of less than 5 percent was treated as significant.

## Results

A total of (n=250) primary care givers completed the self administered questionnaire. More than 60% of them were 40 years of age or less and the majority were males. More than 85% of them were at least graduates. More than 50% of the care givers were first degree relatives, like spouse, or a child. About forty five percent (95% C.I.: 39.03%, 51.37%) of the study respondents had enhanced knowledge about palliative care. Young individuals aged <40 years, with education level of Grade 10, children or relations of the patient were found to have significantly better understanding about palliative care than their counterparts caring for the patient. **(Table 1)**

More than half of them agreed that the person receiving palliative care should be encouraged to carry out normal routine activities or to fulfill all their wishes. Approximately 70% of the respondents agreed with the opinion attitude/view that the person suffering from cancer should be informed about the diagnosis and disease progression. A little less than half 113(45.2%) agreed with a statement describing palliative care, while 103 (41.2%) did not know and 34 (13.6 %) disagreed with the statement. The majority agreed with a statement about the meaning of palliative care, did not know **(Table 2)**

Differences in the mean scores of knowledge of different aspects of palliative care by age, gender, level of education and relationship with the patient were observed. **(Table 3)**

Goals of PC Score (F=13.23; df=3,246; p-value<0.001), Focus of PC Score (F=17.50; df=3,246; p-value<0.001), Team Members of PC Score (F=31.08; df=3,246; p-value<0.001), Settings of PC Score (F=18.15; df=3,246; p-value<0.001), Hospice Knowledge Score (F=4.58; df=3,246; p-value<0.001), Opinion about Provider of PC Score (F=13.65; df=3,246; p-value<0.001), Opinion that Palliative Care should be Offered to Everyone Suffering from an Incurable Disease Score (F=33.16; df=3,246; p-value<0.001), Opinion about best setting to provide PC Score (F=14.64; df=3,246; p-value<0.001) and opinion about the best source of knowledge about PC Score (F=4.89; df=3,246; p-value=0.003) were found significantly different by age of the respondent except 'Opinion about the Needs of Patients Suffering from an incurable Disease Score' (F=0.233; df=3,246; p-value=0.873).

Focus of PC Score (F=17.02; df=1,248; p-value<0.001), Settings of PC Score (F=7.002; df=1,248; p-value=0.009), Hospice Knowledge Score (F=5.12; df=1,248; p-value=0.025), Opinion about Provider of PC Score (F=53.94; df=1,248; p-value<0.001), Opinion about the Needs of Patients Suffering from an Incurable Disease Score (F=28.02; df=1,248; p-value<0.001), Opinion Patient best setting to provide PC Score (F=3.93; df=1,248; p-value=0.049) and Opinion about the best source of knowledge about PC Score (F=11.09; df=1,248; p-value=0.001) were found significantly different by gender of the respondent except Goals of PC Score (F=1.177; df=1,248; p-value=0.279), Team Members of PC Score (F=3.55; df=1,248; p-value=0.061) and Opinion that Palliative Care should be Offered to Everyone Suffering from an Incurable Disease Score (F=1.69; df=1,248; p-value=0.195).

Goals of PC Score (F=8.80; df=2,247; p-value<0.001), Focus of PC Score (F=73.13; df=2,247; p-value<0.001), Team Members of PC Score (F=8.03; df=2,247; p-value<0.001), Hospice Knowledge Score (F=13.42; df=2,247; p-value<0.001), Opinion about Provider of PC Score (F=22.43; df=2,247; p-value<0.001), Opinion about the Needs of Patients Suffering from an Incurable Disease Score (F=33.24; df=2,247; p-value<0.001), Opinion that Palliative Care should be Offered to Everyone Suffering from an Incurable Disease Score (F=18.25; df=2,247; p-value<0.001), Opinion of Patient best setting to provide PC Score (F=11.47; df=2,247; p-value<0.001) and Opinion about the best source of knowledge about PC Score (F=4.13; df=2,247; p-value=0.017) were found significantly different by level of education except Settings of PC Score (F=2.01; df=2,247; p-value=0.136).

Goals of PC Score (F=7.25; df=2,247; p-value=0.001), Focus of PC Score (F=22.53; df=2,247; p-value<0.001), Settings of PC Score (F=17.18; df=2,247; p-value<0.001), Hospice Knowledge Score (F=20.15; df=2,247; p-value<0.001), Opinion about Provider of PC Score (F=11.03; df=2,247; p-value<0.001) and Opinion Patient best setting to provide PC Score (F=16.87; df=2,247; p-value<0.001), Opinion about the best source of knowledge about PC Score (F=3.21; df=2,247; p-value=0.042) were found significantly different for relationship with patient except Team Members of PC Score (F=0.25; df=2,247; p-value=0.776), Opinion about the Needs of Patients Suffering from an Incurable Disease Score (F=3.01; df=2,247; p-value=0.051) and Opinion that Palliative Care should be Offered to Everyone Suffering from an Incurable Disease Score (F=1.58; df=2,247; p-value=0.207).

**(Table 3)**

## Discussion

The concept of palliative care or palliative care as a formal approach towards patients diagnosed with incurable and invariably progressive conditions, is relatively new to Pakistan, in the community and also among physicians. Just a handful of studies have been done on this concept so far in Pakistan. [10,15,16] Aga Khan University Hospital recently set up a formal palliative care program consisting of a section of palliative medicine in the department of Oncology, with dedicated clinics and home based care services. At the same time an online course and workshops on palliative care are being offered to health care professionals. However, awareness in the community at large appears to be limited as it is a new concept in Pakistan. All the respondents in this study were caring for patients with incurable and/or progressive conditions and were therefore, able to assess the needs of these patients in terms of symptom relief and providing comfort rather than futile attempts to cure the disease. They were also aware of the care and treatment being provided for their patient. whether in hospital, at home or in the outpatient clinics. The vast majority 223 (89%) out of the total 250 study participants, were young adults upto the age of 50 years, whereas the remaining few were in the age range of 50 to 60 years. This is in keeping with the fact that care giver's are more likely to be younger and able-bodied, as caring for patients on palliative care can be increasingly demanding as the patient's condition progresses. More than half of the care giver's were male which is in contrast with international studies that have repeatedly found that the majority of care giver's are female.[23] The finding that all of the respondents were literate and the majority of the study participants were at least graduates may have had a bearing on the levels of awareness and knowledge about PCA study in the US found the same association.[21] In this sample of care giver's, half of them were close relatives of the patient, like wife, husband, sister or brother divided almost equally, while the remaining were nurses, nursing attendants or distant relatives. This matches findings in international studies where close family members take on the role of care giver when a spouse, parent, or child or a relative falls ill.[24,25] In the Pakistani setting the care giver is often a relative and often considers the opportunity to be an honor and a privilege. **(Table 1)**

Just over half (54.8%) did not know or did not understand the concept of palliative care while less than half of the caregivers had a correct understanding of the basic concept of palliative care. It is noteworthy that these numbers are comparable with a

large study done in the US in 2019, because the same percentage of caregiver's (55%), had never heard of palliative care, whereas 19.2 % knew what palliative care was and believed they would be able to explain it to someone else. [21,26] A study done on the general population in the US, found misperceptions and negative attitudes towards palliative care even though palliative care is more widely available there. [27]

The PC approach stresses that the diagnosis of an incurable disease does not mean that nothing more can be done for the patient, on the contrary, a great deal can still be done to decrease and control physical and psychological symptoms, social issues and spiritual suffering of the patient.[2] It works in tandem with the 'patient centered approach' that is based on the principle that the patient should be given every opportunity to be involved in all aspects of care starting from complete information about the incurable condition to decision making about treatment options, unless the patient forgoes this right or defers it to a family member.[28, 29, 30, 31] These principles underpin the ethical and professional obligations of this approach. [32] In keeping with this, the majority of the respondents believed that the patient should be informed about the diagnosis of an incurable disease, this matches the findings reported in an earlier paper done in the community health center of the same hospital and international studies done in hospitals and the community.[30,31] This finding should give more confidence to physicians to ask the patient if s/he wants to know the diagnosis and discuss the management options. This is especially relevant when relatives insist that it should not be disclosed or discussed with the patient, again this also fulfils the ethical principle of the patients right to know and patient autonomy.[18,19,32] Similarly, the majority of the respondents believed that patients should be encouraged to carry out routine activities and be facilitated to fulfill their wishes. This is in accordance with the palliative care approach that patients should be enabled to live normal lives and every effort should be made to fulfill their wishes to prevent helplessness and suffering.[1] **(Table 2)**

In contrast to a focused medical approach, the goals of palliative care, therefore, are to ease the suffering of the patient and the family across all its domains, while remembering to stop and reassess at every step to ensure that futile treatments and false hope are avoided so that the patient and family do not suffer needlessly.[1] Whereas PC can be provided in hospital, it can also be provided at home, in the clinic or hospice, which is a place where people with incurable conditions can pass their last months of life. [33] Younger care givers were aware of this, probably because this group was more likely to have greater exposure to electronic media and other sources of information, even if they had been less likely to have had any personal experience of caring for a relative suffering from an incurable disease.[27] In contrast, the oldest age group also had a good understanding of this concept and the obvious explanation was their greater experience and therefore first-hand learning regarding this aspect of life, because by this stage in their lives they would have been more likely to have observed and/or been involved in the care of a family member or a friend suffering from an incurable or progressive condition or disease. All age groups believed that an essential aspect of PC was fulfilling the needs of patients suffering from incurable diseases. **(Table 3)**

Similarly, although all the respondents were educated, participants educated to Grade 10 level at the time of data collection were younger and had better understanding of this concept in keeping with enhanced understanding in the youngest age group of carer giver's, whereas respondents with a higher level of education were older and had a restricted understanding of this concept. Better knowledge and awareness in younger individuals has been noted in a study from the US also. [27]

That there was less variation in correct perceptions about these components across gender is understandable as both have equal opportunity to care for a dying relative, regardless of age and relationship with patient. However, males had a better understanding of the focus of palliative care whereas females had more correct understanding about where PC can be provided.

Children had significantly more information about PC compared to the patient or a spouse as a care giver, again comparable internationally.[27] This is predictable in that younger care giver's have increased access to information technology like the internet and social media along with the education and skills to use it. This is probably because, although affected emotionally, children take on more responsibility in the practical and medical aspects of caring for their parents as patients, are more involved in discussions and management aspects with the medical team, and therefore actively seek information to enhance and improve the care of their affected parent, sparing the other parent of this difficult task. This can also be considered to be reflective of our cultural practices and the dearth of nursing homes and hospices so that children take on the responsibility of caring for parents as they age and/or when they are sick. [34,35] **Table 3**

## **LIMITATIONS:**

As this is a gradually expanding program, the care giver's in the study sample may have acquired some information about the concept of PC during the course of their interaction with the nurses and physicians, therefore the results should be generalized with caution to carer's receiving palliative care in settings without formal programs. This study was done on caregivers associated with a single hospital with a nascent palliative care program in a big city and the results are not generalizable to the rest of the country All of the respondents were literate and as the large majority of the care giver's were educated to at least grade 10, and so the perceptions, knowledge and attitudes of care giver's without at least this level of education is not known. Most of the respondents in the sample were males and may not be representative of the actual gender distribution in other samples and international population where studies have shown that the majority of care giver's are female. Additionally, it does not necessarily imply that most care givers in this setting are males, so it may also not be representative of the actual gender distribution in this population of care givers. Further studies assessing this will make this clear.

## **Conclusion**

Nearly half of the care giver's of patients affected by incurable conditions had a good understanding of the holistic PC approach, even though the discipline of PC does not exist in a formal or organized way in Pakistan. Two foundational aspects showed a consistently good understanding and therefore correct knowledge across age groups, gender, education level, and relationship with the patient. Firstly, that palliative care should be offered to everyone suffering from an incurable disease and, secondly, that this approach encompasses not just physical, but also psychological and social needs of the patient, in addition to the needs of the family caring for the patient. It is necessary to assess perceptions and knowledge of PC in care givers whether family members or professional caregiver's on a wider scale as palliative care programs are established. [36]

The information will enable the development of focused and contextual awareness and education strategies to allow effective utilization of this service which has been shown to increase the quality of life and symptom control in patients with incurable conditions as they progress. [36] Even when health care providers or physicians are reluctant to offer PC as an option due to feelings of failure or lack of information they will be more likely to offer PC or refer appropriately if the care giver is knowledgeable about it and requests it. [4,18]

It is important and essential to develop palliative care services while simultaneously making efforts to increase awareness and knowledge and dispel misperceptions about PC in both patients and care giver's at a public health level.[29,37]

## **Abbreviations**

World Health Organization-WHO

Palliative Care- PC

AKUH-Agha Khan University and Hospital

## **Declarations**

### **-Ethics approval and consent to participate**

This study was approved by the Aga Khan University Ethics Review Committee (Reference No. 3563-FM-ERC-13). Written consent was taken from each participant.

### **-Consent for publication**

Consent to publish the data gathered from the participants without referring to anyone or revealing the identity of any of the participants was taken from each participant

All the authors have given consent for publication of this paper in BMC Palliative Medicine.

#### **- Availability of data and material**

All the data and material used in the conduct of this study is available for review.

#### **- Competing interests**

None of the authors have any competing interests

#### **- Funding**

There was no funding for this study

#### **- Authors' contributions**

The first 2 authors (SS, FQ), were directly involved in the conception, design, conduct, supervision, data collection and final review and approval of the paper. The third author (IA), did all the statistical analysis, wrote the 'Statistical Analysis' section and made the tables. The fourth author (KM) was involved in the design and conduct of the study. She also organized and supervised the data collection. All the authors reviewed and approved the final paper.

---

#### **Acknowledgements**

We acknowledge with gratitude the support and facilitation provided by Zubair Masih RN, in the collection of the data.

#### **Authors' information.**

Sameena Shah was Assistant Professor in the Department of Family Medicine and had a joint appointment in the Palliative Medicine section of the department of Oncology at AKUH during the time this study was conducted and completed. She left soon after, but continued as visiting faculty in the department of Oncology for the next two years. She currently works and lives in Campbell River, BC, Canada.

Faizan Qaisar was the home - based care physician in the Home Health Care Department of AKUH at the time of the conduct and completion of this study. He recently left to work in a different institution.

Khairunnisa Mansoor was the head nurse of the Home Health Care Services of the AKUH at the time and has since joined the School of Nursing and Midwifery SONAM, AKUH and University, as Instructor.

Iqbal Azam continues as Assistant Professor in the Department of Community and Health Sciences of the Aga Khan University.

## **References**

1. <https://www.who.int/cancer/palliative/definition/en/>. Accessed on 28th December, 2019
2. Higginson IJ, Evan CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *The Cancer Journal*. 2010 Sep 1;16(5):423-35.
3. Mularski, Richard A., et al. "Proposed quality measures for palliative care in the critically ill: A consensus from the Robert Wood Johnson Foundation Critical Care Workgroup." *Critical care medicine* 34.11 (2006): S404-S411.
4. McAteer R,

Wellbery C. Palliative care: benefits, barriers, and best practices. *Am Fam Physician*. 2013 Dec 15;88(12):807-13. 5. Kavalieratos D, Corbelli J, Zhang D, Dionne-Odom JN, Ernecoff NC, Hanmer J, Hoydich ZP, Ikejiani DZ, Klein-Fedyshin M, Zimmermann C, Morton SC. Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *Jama*. 2016 Nov 22;316(20):2104-14. 6. Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, Gomes B, Harding R. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *The Lancet Global Health*. 2019 Jul 1;7(7):e883-92. 7. World Health Organization. Global Action against Cancer. Geneva: World Health Organization/UICC; 2003) 8. <https://www.who.int/news-room/fact-sheets/detail/cancer>. Accessed on 28th Dec. 2019. 9. Clark D, Baur N, Clelland D, Garralda E, López-Fidalgo J, Connor S, Centeno C. Mapping levels of palliative care development in 198 countries: the situation in 2017. *Journal of pain and symptom management*. 2019 Nov 22. 10. Shad A, Ashraf MS, Hafeez H. Development of palliative-care services in a developing country: Pakistan. *Journal of pediatric hematology/oncology*. 2011 Apr 1;33: S62-3. 11. Docherty A, Owens A, Asadi-Lari M, Petchey R, Williams J, Carter YH. Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliative Medicine*. 2008 Mar;22(2):153-71. 12. Benini F, Fabris M, Pace DS, et al. Awareness, understanding and attitudes of Italians regarding palliative care. *Ann Ist Super Sanita* 2011; 47(3): 253–259. 13. Will Patients Want Hospice or Palliative Care if They Do Not Know What It Is? Matsuyama, Robin K. PhD; Balliet, Wendy PhD; Ingram, Kathleen PhD; Lyckholm, Laurie J. MD; Wilson-Genderson, Maureen PhD; Smith, Thomas J. MD *Journal of Hospice & Palliative Nursing*: January-February 2011 - Volume 13 - Issue 1 - p 41-46 14. Hirai K, Kudo T, Akiyama M, et al. Public awareness, knowledge of availability, and readiness for cancer palliative care services: a population-based survey across four regions in Japan. *J Palliat Med* 2011; 14(8): 918–922 15. Abbas, S. Q., et al. "Awareness of palliative medicine among Pakistani doctors: a survey." *JPMA*. 54.4 (2004): 195-198. 16. Singh T, Harding R. Palliative care in South Asia: a systematic review of the evidence for care models, interventions, and outcomes. *BMC research notes*. 2015 Dec;8(1):172. 17. R9 Gelfman LP, Meier DE, Morrison RS. Does palliative care improve quality? A survey of bereaved family members. *Journal of pain and symptom management*. 2008 Jul 1;36(1):22-8. 18. Love AW, Liversage LM. Barriers to accessing palliative care: a review of the literature. *Progress in Palliative Care*. 2014 Feb 1;22(1):9-19. 19. Choi S, Seo J. Analysis of caregiver burden in palliative care: An integrated review. In *Nursing forum* 2019 Apr (Vol. 54, No. 2, pp. 280-290). 20. Veloso VI, Tripodoro VA. Caregivers burden in palliative care patients: a problem to tackle. *Current opinion in supportive and palliative care*. 2016 Dec 1;10(4):330-5. 21. Dionne-Odom JN, Omstein KA, Kent EE. What do family caregivers know about palliative care? Results from a national survey. *Palliative & supportive care*. 2019 Apr 8:1-7. 22. <http://www.merriam-webster.com/dictionary/caregiver> Accessed on 28th January 2019. 23. Dahlberg L, Demack S, Bamba C. Age and gender of informal carers: a population-based study in the UK. *Health & social care in the community*. 2007 Sep;15(5):439-45. 24. Morris SM, King C, Turner M, Payne S. Family carers providing support to a person dying in the home setting: a narrative literature review. *Palliative medicine*. 2015 Jun;29(6):487-95. 25. Ramirez A, Addington-Hall J, Richards M. ABC of palliative care. The carers. *BMJ: British Medical Journal*. 1998 Jan 17;316(7126):208. 26. Claxton-Oldfield S, Claxton-Oldfield J, Rishchynski G. Understanding of the term 'Palliative Care': a Canadian survey. *Am J Hosp Palliat Care* 2004; 21(2): 105–110 27. Taber JM, Ellis EM, Reblin M, Ellington L, Ferrer RA. Knowledge of and beliefs about palliative care in a nationally-representative US sample. *PloS one*. 2019;14(8). 28. Care CT. Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies. New York: Center to Advance Palliative Care. 2011. 29. Walczak A, Butow PN, Clayton JM, Tattersall MH, Davidson PM, Young J, Epstein RM. Discussing prognosis and end-of-life care in the final year of life: a randomised controlled trial of a nurse-led communication support programme for patients and caregivers. *BMJ open*. 2014 Jun 1;4(6):e005745. 30. Zafar W, Hafeez H, Jamshed A, Shah MA, Quader A, Yusuf MA. Preferences regarding disclosure of prognosis and end-of-life care: A survey of cancer patients with advanced disease in a lower-middle-income country. *Palliative medicine*. 2016 Jul;30(7):661-73. 31. Ishaque S, Saleem T, Khawaja FB, Qidwai W. Breaking bad news: exploring patient's perspective and expectations. *Journal of the Pakistan Medical Association*. 2010;60(5):407. 32. Mohanti BK. Ethics in palliative care. *Indian Journal of Palliative Care*. 2009 Jul;15(2):89. 33. <https://www.merriam-webster.com/dictionary/hospice>. Accessed on 30th June 2019. 34. Shad A, Ashraf MS, Hafeez H. Development of palliative-care services in a developing country: Pakistan. *Journal of pediatric hematology/oncology*. 2011 Apr 1;33: S62-3. 35. Palliative Care in the Muslim-Majority Countries: The Need for More and Better Care. *Contemporary and Innovative Practice in Palliative Care*. Deena M. Aljawi<sup>1</sup> and Joe B. Harford<sup>2</sup>. 2012. 36. Dionne-Odom JN, Azuero A, Lyons KD, Hull JG, Tosteson T, Li Z, Li Z, Frost J, Dragnev KH, Akyar I, Hegel MT. Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: outcomes from the ENABLE III randomized

controlled trial. Journal of clinical oncology. 2015 May 1;33(13):1446-37. Ddungu, Henry. "Palliative care: what approaches are suitable in developing countries? " British journal of haematology 154.6 (2011): 728-735.

## Tables

Due to technical limitations the tables are available as a download in the Supplemental Files.

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [STROBECHECKLISTDOCUMENT.docx](#)
- [Finalquesttionnaire2urduandenglishcombined.2015.docx](#)
- [MethodsforEstimatingPrevalenceRatio.pdf](#)
- [2003AlternativeforLogisticRegression.pdf](#)
- [Tables.pdf](#)