

Original Article

Perceptions of Healthcare Workers Regarding Palliative Care Services in a Tertiary Care Teaching Hospital in North India – A Mixed Methods Observational Study

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ABSTRACT

Objectives: Cancers and various terminal illnesses need integrated palliative care with curative management, but, unfortunately, our health care system mainly focuses on the treatment of disease. Lack of awareness, difficulty in pain management and untrained staff are some of the challenges in palliative care services.

The study was done to explore the perception of healthcare workers regarding availability, utilisation and challenges in the delivery of palliative care services.

Material and Methods: A mixed method study was conducted at tertiary care teaching hospital in North India. Qualitative approach using interviews and focus group discussions (FGDs) among healthcare workers was done to understand their knowledge, perception, barriers and challenges in implementing palliative care services. One hundred and thirteen healthcare workers were interviewed using a semi-structured questionnaire and FGD was conducted to gain more insight into the issues of palliative care. The data obtained was analysed with the help of computer software Microsoft Excel and SPSS version 23 for windows. The data was presented as proportion and mean (S.D.) as deemed appropriate for qualitative and quantitative variables respectively. Thematic analysis was done with the data of FGD.

Results: The knowledge, attitude and practices regarding palliative care were poor across the HCW. During FGD with faculty and residents, the participants showed great concern about the absence of palliative care across many specialties while expressing an acute need for the establishment of a separate interdisciplinary unit on palliative care to improve the quality of life in patients.

Conclusion: The study shows that there are gaps that need to be addressed to make palliative services available in our hospital.

Keywords: Barrier, Focus group discussion, Interview, Palliative care, Qualitative

INTRODUCTION

Palliative care is 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 through early identification and impeccable assessment, and treatment of pain and other problems-physical, psychosocial and spiritual.^[1] Palliative care needs to be given right from the point a disease is diagnosed until the end of life. There is enough evidence that suggests that palliative care, with its focus on the

management of symptoms, psychosocial support, and assistance with decision-making has the potential to improve the quality of care and reduce the use of medical services.

Each year, an estimated 56.8 million people need palliative care, 76% of whom live in low- and middle-income countries. Globally, it is estimated that palliative care was needed in 45.3% of all deaths which occurred in 2017.^[2]

The Indian Association of Palliative Care was formed, in 1994, in consultation with the World Health Organisation

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Table 1: Knowledge about palliative care as reported by faculty and residents.

Questions	Number/response	Percentage
Palliative care services		
1. Palliative care should be given to		
a. Patient	66	58.4
b. Patient and family	08	7.1
c. All (patients, family and caregivers)	39	34.5
2. Palliative care should be provided at		
a. Home	86	76.1
b. Hospice*	7	6.2
c. Palliative care centre	9	7.9
d. Health Centre	11	9.8
3. Knowledge of step ladder approach		
a. Yes	89	78.8
b. No	24	21.2
4. Knowledge of use of narcotic drugs in cancer patients		
a. Yes	89	78.8
b. No	07	6.1
c. Do not know	17	15.1
5. Knowledge about availability of palliative care services in India		
a. Government medical colleges/tertiary institutions	86	76.1
b. All health institutions	25	22.1
c. None	02	1.8
6. Initiation of palliative care in patients vis-a-vis stage of cancer		
a. At the time of diagnosis	36	31.8
b. In the final stage of disease	74	65.4
c. Anytime in the course of illness	03	2.6
7. **Pre-requisites for establishment of palliative care unit		
a. Manpower	92	NA
b. Space	78	
c. Medicine	69	
d. Tumour board	15	
e. Finance	53	
8. Which is the preferred drug for the management of pain in cancers and chronic diseases		
a. Morphine	97	85.9
b. Tramadol	4	3.5
c. NSAIDS	12	10.6

**Multiple responses

and Government of India. In India, currently, there are approximately 908 palliative care centres, out of which 841 (92%) are in Kerala and the rest 67 (8%) are in other states.^[3]

Cancer is the largest single disease group, where palliative care is required, while other conditions such as dementia, HIV, and cerebrovascular diseases also require palliative care.^[2] Eighty percent of patients with cancer suffer from moderate-to-severe pain in their terminal stages of disease. As per World Cancer Report, 1 in 10 Indians will develop cancer during their lifetime and 1 in 15 will die of this disease. As per the World Cancer report 2018, 1.16 million new cancer cases, 784,800 cancer deaths and 2.26 million 5-year prevalent cases were reported in India.^[4]

The scarcity of palliative care services can be gauged from the 2011 study of 234 countries/regions that revealed the

fact that palliative care services were only well integrated with 20 countries, while 42% had no palliative care services at all and a further 32% had only isolated palliative care services.^[5]

It is reiterated that palliative care services are available only in a few states of India and the situation of palliative care delivery could be described as patchy, unorganised, informal and unreliable. Even in Government Medical College, we expect the burden of people who require palliative care would be as high (if not more) as in other tertiary care centres in our country, though we do not have the exact data to specify numbers. The present study was, thus, planned with the intent to explore the perception of health care workers regarding availability, utilisation and challenges in the delivery of palliative care services in our institution and associated hospitals.

Table 2: Attitude of faculty and residents regarding palliative care.

Questions	Response	Percentage
1. How long the palliative care should last		
a. Till the patient is alive	102	90.3
b. After the death of patient	11	9.7
2. Problems faced in making available pain alleviating medicines in patients requiring palliative care		
a. Legal	23	20.4
b. Procurement issues	75	66.4
c. Do not deal	15	13.2
3. Trained Faculty members for Palliative Care Services in Regional Cancer Centre		
a. Untrained	99	87.6
b. Trained	14	12.4
4. *Community perception of Patients with Cancer and Chronic Diseases		
a. Ignorance	18	NA
b. Abandonment	16	
c. Sympathy	96	
d. Stigma	22	

*Multiple responses

Table 3: Elements of *palliative care as reported by faculty and residents.

Elements	Response (multiple)
Analgesia	86
Nutrition	46
Counselling	79
Physiotherapy	42
Spiritual	22
Occupational	15
Educational	16

Table 4: Symptoms in cancers and chronic diseases which require palliation as reported by faculty and residents.

Symptoms	Response (multiple)
Depression	87
Immobilisation	65
Disease-specific symptoms	100
Disease and treatment-related complications	80
Symptoms due to inadequate nutrition	72

MATERIAL AND METHODS

A mixed-method observational study comprising both qualitative and quantitative components was conducted in Government Medical College and its associated hospitals for 1 year from November 2018 to October 2019 after seeking approval from the Institutional Ethical Committee, vide letter no: TEC/GMC/2019/891.

To explore the palliative care component in cancer treatment, we use qualitative methods, wherein a semi-structured

Table 5: Concerns of patients after being diagnosed with cancer or a chronic illness as reported by faculty and residents.

Issues of patients after diagnosis	Response (multiple)
Financial	66
Fear of life	82
Quackery	19
Social stigma	19
Anxiety	94
Caregiver issues	35

questionnaire having a set of common questions for doctors, nurses and other healthcare workers was designed and pilot tested to obtain information on the type, availability, extent and nature of palliative care services offered to patients in tertiary care and associated hospitals.

A list of all staff members working in specialties, where palliative care is required, was drawn. The investigator approached the respective head of the department and solicited his/her permission for interviewing the staff working under his/her control. All available staff members, which showed interest and consented to participate were interviewed by the investigator using a pre-designed semi-structured questionnaire. Thus, a convenience sample of a total of 113 healthcare workers was selected for the study.

The information collected from pilot interviews and observations of the investigator was used to design a questionnaire for focus group discussions (FGD). FGD was planned to be held with stakeholders who are involved in the provision of palliative care to patients. This included doctors and administrators at different levels like officials from the Directorate Health Services. To gain more insight into the issues about palliative care, probing was done to discuss the attitude and perception of healthcare providers regarding palliative care. Information regarding barriers, difficulties and challenges in addressing palliative care services was also elicited.

FGD was conducted as per protocol, where in-house discussions among core investigators were held and the moderator and assistant moderator for each discussion were nominated.^[6] Moderators and assistant moderators communicated with healthcare personnel of various departments to seek their availability. The 10–12 participants were short-listed for FGD and 10 participants came for the FGD. At the start of FGD, the moderator welcomed all the participants and introduced himself and the assistant moderator to them which was followed by a brief introduction of the participants. Moderator gave an overview of the topic and the purpose of conducting FGD. Consent forms were signed by the participants. Moderator initiated the discussion. The whole session was audio recorded. It took approximately 45 min to complete the FGD. In the end, the briefing of the session was done by moderator and assistant moderator for about 10–15 min. Transcription of focus group was prepared within 5 days of the discussion.

Plan of analysis

The data obtained were analysed with the help of computer software Microsoft Excel and SPSS version 23 for windows. The data were presented as frequency and percentages. The data of audio recorded FGD's was transcribed word to word and thematic analysis was done. The transcripts were supplemented by notes by the moderator and from debriefing sessions. The cut and paste method was employed to identify codes. The constant comparison method was used to draw themes and categories.

RESULTS

KAP study on palliative care and its associated features was conducted among 113 health care workers including faculty members and residents working in Government Medical College and its associated hospitals.

Opinion of faculty and residents regarding palliative care was good in some aspects, whereas poor in others as only 34.5% opined that palliative care should be given to patients, family and caregivers. Four out of five residents were fully aware of the step ladder approach and use of narcotics drugs in cancer patients. Two-third believed that palliative care should be provided only at the time of final diagnosis [Table 1].

Hundred percentage of HCW's believe that early integration of palliative care can improve the quality of life in patients suffering from terminal illnesses [Table 2].

The percentages are not given because the response obtained was a combination of options. Management of pain and a provision for counseling were the elements that were mostly highlighted by the respondents [Table 3].

Apart from the disease symptoms which require palliation, depression, immobilisation due to prolonged illnesses, complications of the disease and deficiencies due to poor nutritional intake also need palliative care [Table 4].

The majority of doctors highlighted issues related to finance, fear of life and anxiety concerned with the disease as the most important ones [Table 5].

Themes that emerged after analysis of FGD

Perception of HCW about palliative care

The subthemes related to the perception of healthcare workers are discussed below:

Equating palliative care with rehabilitative care

Most healthcare workers equated palliative care with rehabilitative care.

'Sometimes we go for laryngectomy and the voice is gone. We accordingly rehabilitate the patient that how he will communicate with others such as oesophageal voice, ek electronic voice bhi hoti hai jisko hum bolte hain retro larynx and oesophageal voice.'

Poor understanding of palliative care

Most of the healthcare workers believe that there is lack of understanding among them about palliative care needs of the terminally ill or cancer patients.

'Whenever a patient or an attendant comes with the complaint of pain, we look at the diagnosis and say we can't do anything about it. This is something you have to live with. Hence, the concept of attempting to relieve a person's suffering is not there, is not ingrained in us.'

'We are treating patients with our own understanding. We are not taking care of all components of palliative care. There is no special department for this purpose and no awareness. Only 5–10% of doctors know about palliative care.'

Commencement of palliative care

Lack of consensus was there among healthcare workers with regard to initiation of palliative care.

One of the healthcare workers said;

'Advanced stages especially what we call metastatic stage or when the symptom burden of patient is such that you cannot cure it. These are the two target groups where you need to incorporate palliative care.'

Another Quoted;

'I think they have to go simultaneously hand in hand. We cannot make a transition from curative to palliative care abruptly. It has to go hand in hand simultaneously. All the options have to be explained to the patients and the attendants right from the beginning because a person will also need time to understand and then see the progress.'

Barriers in palliative care practices

Lack of infrastructure/staff for the provision of palliative care

Due to excessive workload, the doctor who is treating patient cannot provide palliative care to the patient which is augmented by lack of supporting staff.

'We see many patients who actually need palliative care'. Sir, many times we get patients with end stage malignancies, end stage liver disease, patients who cannot afford 30–40 lakhs or E-S Renal disease. We know that they cannot afford a renal transplant or dialysis. Hence, we want these patients to be as comfortable as possible before they die, but the problem is that since we do not have a separate department or unit to provide care. At the most we tell them that this patient is not going to survive and you can take this patient home but that is not how palliative care works in my opinion.'

Unavailability of OPIOIDS

Much cannot be done for the pain relief of the patients as opioids most of the time are unavailable or less in quantity.

'I say it like this, – the biggest hurdle in the introduction of PC is non-availability of opioids.'

Lack of team approach

Many participants opined that even though the prognosis is bad, the patient cannot be helped in the absence of a team and a separate palliative care unit. One participant expressed it as ‘Doctor saeb says ki iska prognosis theek nahi hai, bhai isko ghar lejao. Iska kya karein. It has to be teamwork’ (The doctor says that the disease does not have a good prognosis. Take the patient home. What can be done?). ‘Patients as well as the attendants’ psychosocial needs and the spiritual needs also need to be considered. We have to expand our horizon. That’s what total palliative care means’.

Communicating with patients and attendants

Communicating with patients and attendants was one of the most important barriers identified. Issues such as discussing the diagnosis, extent of disease and possible modalities of treatment were chief hurdles. This dilemma was put forward by one participant as ‘It is a myth that patient should not be told. It is not whether to tell or not. It is how to tell and when to tell. You have to tell’.

Despite the prevailing issues, the drivers for the establishment of palliative care were very strong. Major issues highlighted during FGD with faculty and residents are given in Figure 1.

DISCUSSION

We used qualitative techniques to enhance our understanding of palliative care by using an evidence-based approach; we will be on stronger turf to advocate the provision of palliative care in our and other healthcare institutions across our state. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and

spiritual needs and to facilitate patient autonomy, access to information and choice.

FGD among healthcare workers was done to explore their views on palliative care. The vision regarding palliative care was found to be narrow, restrictive and speciality oriented. The issues highlighted by them on lack of palliative care services were an administrative failure, lack of an interdisciplinary approach, dearth of staff and treatment mind-set. These findings are in corroboration with the study done in southwest Ethiopia.^[7]

In our study, patients were given palliation majorly in the form of chemotherapy which cannot be considered in any way a comprehensive form of palliative care. A study done by Payne SA pointed out that little is gained in treating the patients who do not respond to chemotherapy, and moreover, it may add to the distress in their remaining lives.^[8]

Enough evidence exists that comprehensive palliative care has the potential to deliver better quality of life in all domains in cancers and other chronic diseases.^[9-13] However, study conducted by Witkamp FE *et al.* reported no difference in QoL or mood outcomes after giving palliative care.^[14]

Management of pain is a big issue in palliative care. Our institute fares poorly as far as provision of palliative care is concerned, with even opioids and other essential narcotic drugs are not available regularly for symptomatic management of terminally ill patients. Morphine is not regularly available to the patients mostly due to procurement issues and the absence of a palliative care department. According to a study by Centeno C *et al.*, there is an increase in total opioid prescription in cancer patients, where palliative care is given by the palliative team.^[15]

To gain further insight on various facets of palliative care, we administered a questionnaire for assessing knowledge, attitude and practices about palliative care among faculty, residents and healthcare workers. Nonetheless, the practitioners stressed on a comprehensive package for palliative care including training of doctors and healthcare workers. They expected that given a more comprehensive package, the QoL of patients can be made better. Many authors have conducted qualitative studies among professionals caring for cancer patients and knowledge, attitude and practices were seen to be poor among all cadres of health-care professionals.^[16-18] The results are in agreement with our study.

Communication was a lacuna that was predominantly highlighted by the professionals in our FGD. Our healthcare workers feel that it was necessary to communicate with the patient about the outcome of disease but were not sure about the time. Udo C conducted focus group interviews to explore palliative home care physicians’ experiences regarding end-of-life breakpoint communication. The result showed that this communication needs to be initiated at an early stage of the disease.^[19]

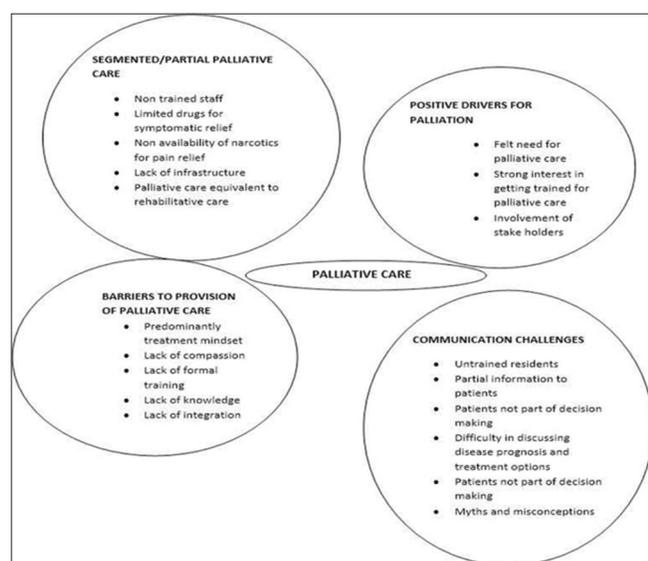


Figure 1: Major issues highlighted during focus group discussion with faculty and residents.

Unfortunately, in many healthcare setups, only a minimal level of palliative care is available. This deprivation owes in part to lack of trained human resources and infrastructure, but some of it can be attributed to just being ignorant about the needs for palliative care like provision of symptomatic relief including the provision of narcotics in the hospitals which alone can alleviate the poor QoL in patients.

CONCLUSION

We intend to share our observations with other stakeholders to plan and expand palliative care not only for patients of cancer but also for terminally ill patients suffering from other NCDs. We suggest that QoL can be improved in patients with cancers, even if a basic package of palliative care is offered to the patients.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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