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Study on Palliative Care Services in A Tertiary Care Hospital

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ABSTRACT

Palliative Care refers to patient-centred and family-centred care and is not disease-focused and if necessary extends support to the family in bereavement. The introduction of palliative care in undergraduate medical curriculum is a necessary step in the development of formal system of education towards End of Life care and of palliative care in India. The present study attempted to understand the knowledge of undergraduate medical students pertaining to various aspects of palliative care. To study the need for Palliative Care Services at a tertiary care hospital. A structured, pretested self-administered questionnaire on palliative care was used to collect information. Morbidity and Mortality data was collected and analyzed for the need for palliative care services. Good knowledge was observed amongst students regarding certain aspects like Palliative Care (PC) uses a team approach as 318 (86.4 %), students correctly stated that PC integrates psychological and spiritual aspects as 305 (82.9 %), students answered incorrect that PC is provided only in hospitals as 317 (86.1 %).The study revealed the content of training program required for undergraduate medical students pertaining to palliative care.

Keywords: Palliative Care, Undergraduate Medical awareness, End of Life care, Prevalence

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INTRODUCTION

Palliative care improves health care quality in three domains, -The relief of physical and emotional suffering, - Improvement and strengthening of the process of patient–physician communication and decision-making, - Assurance of coordinated continuity of care across multiple healthcare settings—hospital, home, hospice, and long-term care.^[1] Despite its limited coverage, palliative care has been present in India for about 20 years. Palliative medicine is the name given to the developing specialty of healthcare focused on treating those with advanced disease where the goals are to relieve suffering and improve quality of life. Palliative Care (PC) is the active total care of patients whose disease is not responding to curative treatment. Commonly these patients suffer from severe existential distress related to issues of their past (guilt, remorse, unfulfilled expectations), their altered self-image (dependency, altered family, professional roles) and their future (dashed hopes, meaning in the time remaining, fear of death).^[2-3] PC refers to patient- and family-centred care and is not disease-focused and if necessary extends support to the family in bereavement. Quality assurance data worldwide suggests that the current healthcare system is providing inadequate care for the dying. Several studies have shown that basic knowledge regarding PC amongst medical students is inadequate and it needs to be reinforced. Focused training in PC and end-of -life (EOL) teaching methods is essential to strengthen the knowledge and skills of medical students regarding PC.^[4] The exploration of PC has not extended, to date, to the knowledge and understanding of the Indian population. It is this gap in research and knowledge that this project aimed to fill, the need for patients with incurable disease like cancer, along with an exploration of the medical students' knowledge, awareness, attitude and confidence pertaining to various aspects of PC and also public awareness of PC. A needs assessment provides information so that appropriate and realistic implementation and evaluation plans can be developed. It also evaluates the educational need for a curriculum and possible content and instructional strategies.^[5]

Aim: To study the need of Palliative Care Services at a tertiary care hospital.

Objectives: 1) To evaluate the need for palliative care service. 2) To assess the knowledge and awareness of palliative care among the medical students.

Methodology: The study was conducted in duration of 6 months (January to June) in this tertiary care hospital with ethics committee approval obtained prior to the study.

To assess the need of Palliative Care: A retrospective study was conducted to assess the number (no.) of cancer patients registering annually in the Cancer Research Centre. The registers of three years - 2011, '12, and '13 in the medical records department were scrutinized. The estimated number of people in need of PC was calculated based on the mortality data.

To assess the knowledge and awareness of medical students: A cross-sectional descriptive study was conducted. Source of data was administering questionnaires to the medical fraternity. Target population among the medical fraternity involved final year undergraduate (U.G), intern and postgraduate (P.G) students. The students were a mix of majority Indian and few foreign nationals. A self-explanatory and structured questionnaire administered to the medical fraternity was divided into 3 sections. First section was to check if they had any PC training, the second section involved a 15-point questionnaire which was divided into 3 major sub-section regarding, knowledge having 8 stems, attitude and confidence having 3-4 stems under each section. The third section assessed future education topics required by the students. At the end of the questionnaire, a provision for general comments/ suggestions by the respondents, if any, was provided. The questionnaires were internally validated and its reliability also checked using test re-test where after a time interval of 1 month the questionnaire was re-administered to participants either by email or going personally. In order to find out whether different groups of people have different opinions some basic information about them were collected such as age, sex and discipline which were confidential and anonymity was maintained throughout the study. The data was collected by distributing the questionnaires in the classroom, talking with the interns and P.Gs in their respective wards, OTs and during rounds. The students who participated in the study were fully informed about the design and purpose of the study and the participation was voluntary.

RESULTS

The study was carried out with the specific objective of finding out the need of PC service in Cancer Hospital and Research Centre of the hospital, based on the no. of deaths of cancer/ year, using the recommended WHO formula.

For the years 2011-2013 the average estimated no. of people in need of PC service based on the cancer deaths/ year is as per below Table 1.

Table 1:- Estimated number of people in need of Palliative Care at this Hospital

	Cancer deaths	Patients in need of PC		Caregivers per patient	Total number of people in need of PC
	Number	80 %	Number	Number	Number
	(A)	(B)	(C=A*B)	D	C*D
Adults	200	0.8	160	4	640
Children	17	0.8	13.6	3	40.8
Total	217	1.6	173.6	7	680.8

The above table shows an average of 217 people of these 200 adults and 17 children approximately died in each year from different types of cancer. According to WHO, it is assumed that 80% of terminal cancer patients will require Palliative Care. Thus, out of 217 people around 174 people were in need of PC which is to be then multiplied by the assumed number of caregivers each patient would have had. Thus calculating these, it is observed that around 681 people were in need of PC of these around 640 were adults and around 41 were children.

A similar study was conducted by WHO in five sub-Saharan African countries using the same above mentioned method, where a rapid assessment of PC needs at the End Of Life based on the number of deaths from cancer and HIV/AIDS were made. It was found that the no. of people needing PC each year was estimated to be at least 690 800 (Cancer+ HIV/AIDS) or 0.5% of the total population of these countries.^[6]

In 2011 India had a population of 1241.5 million which is almost 50% more than the population of all the Sub-Saharan African countries combined which was around 874.8 million. Together with China, India has the second largest population in the world. Thus the human need to the felt deprivation of PC i.e the necessity/ obligation, something required because it's important/ essential rather than desirable can be clearly marked and identified in the Indian scenario.^[7]

Our study, the patients with cancer in the terminal stage were considered. PC emphasizes service for patients with life-threatening diseases from the time of diagnosis till death. With 2000 new cancer cases registered at the hospital every year in addition to people who already have been diagnosed and are regular visitors at the hospital for follow-up and 80% of terminal cancer patients, the no. of people in need of PC increases. The data for the same is presented in Table 2.

Table 2: Estimated total number of people in need of PC

	Cancer Patients	Caregivers per patient	Total number of people in need of PC
	Number	Number	Number
	(A)	D	C*D
Adults	5233	4	16,745.6
Children	581	3	1,394.4
Total	5814	7	18,140

The above table shows average total no. of cancer patients registered in the hospital each year, of these 5233 adults and 581 children registered for different types of cancer. This is then multiplied by the

assumed no. of caregivers each patient would have had. Thus calculating these, it is observed that around 18,140 people were in need of PC of these around 16,746 were adults and around 1,394 were children.

During the study it was observed that the cancer hospital had setup up a Palliative Care unit in March 1993 and upgraded with Psycho-Oncology clinic in March 1995, which provided psychological & psychiatric services to both the patient and their attendants. A team of professionals provided PC in the patients' homes. This type of domiciliary care was available only in few centres in this state. Oral morphine and other supportive care were given to the patient and the care givers. 1204 had availed the services of this clinic till 2002. The clinic also conducts group therapy (Malayalam and Kannada) for the relatives of cancer patients regularly. The clinical impression of the psycho oncology team is that the patients are benefiting from their practices. Around 120 patients were enrolled in the year 2007-2008. The PC unit is no longer working and was soon shut in the year 2009 as the main consultant and few professionals left the institution. Interview with these depts. reveal that after the PC unit was shut only few patients are referred to them by the doctors as they still believe in curative treatment and not in relieving the pain and giving the patient a comfortable and pain-free life and terminally ill patients are not given any proper advice by the doctors. The old loyal staffs still on the payroll and working with the hospital indicated when the unit was established with a dedicated team of professionals lot of referrals used to come and it was helping the patient in all possible way.

The values of the sample size for medical students were 368 and for general public were 138. Out of the 368 medical students, there were 119 interns of these 63 were male and 56 were females, 108- P.Gs of these 87 were males and 21 were females, 141- U.Gs of these 77 were males and 64 were females. Out of the 138 general public, there were 48 males and 90 females.

Good knowledge was observed amongst students regarding certain aspects like PC uses a team approach as 318 (86.4 %) (Statement 4), students correctly stated that PC integrates psychological and spiritual aspects as 305 (82.9 %) (Statement 5), students answered incorrect that PC is provided only in hospitals as 317 (86.1 %) (Statement 6), students answered incorrect that PC is provided only for cancer as 337 (91.6 %) (Statement 8).

Amongst 364 students around 50% of them were wrong about the definition of PC as stated by WHO that it is a care for prevention and relief of suffering by means of early identification, impeccable assessment and treatment.

According to 27% of the students PC and hospice care reflect the same wherein they are not which is comparable to other studies wherein students are not aware about the difference of PC and hospice care. 34.2 % students were not aware regarding that dentists play a role in PC, comparatively good awareness and perception level about oral care in palliative treatment was observed among dental students in a rural dental college as 81.55%.^[8]

Students had a high level of knowledge that PC is not only provided for cancer (91.6 %) compared to medical students in a rural hospital in Maharashtra where out of 109 students 17.43 % believed PC is indicated only in cancer patients and about 23.85 % thought PC is needed only for geriatric population.^[9]

Saini R et.al conducted a study to determine the current knowledge and awareness among undergraduate dental students in a rural dental college regarding palliative medicine and the role of dentist in palliative team. On an average, 59.23% were correct and 40.67% were incorrect for knowledge about palliative medicine, while 81.55% were correct and 18.45% were incorrect regarding awareness about oral care in palliative medicine. 75% students knew that in PC an interdisciplinary approach is required. Results indicate that students had good awareness and perception level about awareness of oral care in palliative treatment.^[8] From the above Questionnaire on Attitude and Confidence levels, it was observed that 33 students (8%) were not comfortable caring for a dying patient, 68 (18%) were unsure/ mixed, 267 students (73%) were comfortable caring for a dying patient (Statement 9). 82 students (22%) were not comfortable talking to families about death, 101 (27.44%) were unsure/ mixed, whereas only 185 students (50%) were comfortable caring for a dying patient (Statement 10), 222 students (60.3%) agreed that families have the right to refuse a medical treatment even if that treatment prolongs life, 61 students (16.5%) were unsure/ mixed, whereas 85 students (23%) disagreed (Statement 11), 52 students (14.1%) agreed that patient should experience

discomfort prior to next dose of medication, 77 students (20.9%) were unsure/ mixed, whereas 239 students (64.9%) disagreed (Statement 12), 169 students (45.9%) agreed they were confident answering patients questions about the dying process, 139 students (37.7%) were unsure/ mixed, whereas 60 students (16.3%) disagreed (Statement 13), 139 students (37.7%) agreed they were confident reacting to and coping with terminal delirium, 163 students (44.2%) were unsure/ mixed, whereas 66 students (17.9%) disagreed (Statement 14), 192 students (52.1%) agreed they were confident reacting to and coping with limited patient decision-making capacity, 130 students (35.3%) were unsure/ mixed, whereas 46 students (12.5%) disagreed.

Table 3: Future Education indicated by the medical students of different discipline

Topics	No. of students requiring education	Percent (%)
Pain assessment and management	204	55.4
EOL communication skills	214	58.1
Spirituality and cultural aspects EOL	93	25.2
Dealing with nausea and vomiting	94	25.6
Dealing with Constipation	62	16.8
Dealing with terminal delirium	138	37.5
Use of intravenous hydration and/or non – oral feeding	146	39.6
Dealing with terminal Dyspnoea	143	38.8
EOL ethics	189	51.3

A survey conducted for all the residents in Children’s Hospital of Pittsburg, indicated residents required training in pain management and the next 4 educational needs were communication skills, namely, discussing prognosis, bad news, code status and talking with children about end-of-life care.^[10] Whereas in this study future education regarding pain management and EOL communication was rated almost equal.

Assessing cancer palliative care (PC) needs is in many ways equivalent to assessing an urgent humanitarian need to reduce unnecessary suffering of patients and their families. It is important to bear in mind that although in the medium to long term – effective prevention, early detection and treatment will reduce PC needs, but PC needs will never be eliminated, because some types of cancer will inevitably remain fatal for some patients.^[1]

CONCLUSION

The study demonstrated average knowledge among the medical fraternity, as the participants were unsure reacting to certain aspects of End of life care. There is a lacuna in the delivery of palliative care services and hence there is urgent need to augment educational curriculum to provide training, and focused skills.

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