

PALLIATIVE CARE- AWARENESS IN GENERAL POPULATION IN METROPOLITAN CITIES OF WESTERN INDIA

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ABSTRACT

BACKGROUND

Adequate symptom relief is a central aspect of medical care in all patients, especially those with incurable diseases. Treatment may help in symptomatic relief, but in some cases palliation is needed. Sometimes, as disease progresses, palliation becomes the paramount goal of care. We have conducted the study to look for the experience and scenario of patients towards PC.

The aim of the study is to clarify the number of palliative care services and to obtain information regarding patient's view about palliative care, we have conducted the study.

MATERIALS AND METHODS

A cross-sectional non-experimental survey design was used. We have recruited 288 patients. Participants were invited to participate via personal visits, telephonic and email invitations, hospital visits and personnel interview. They were given forms with predefined questionnaire.

RESULTS

Through this survey, we got the information regarding geographical location, experience, disease from which patient is suffering. Along with this, we also got the information about need of Palliative Care (PC) based on age group and organ system involved.

CONCLUSION

Present study tells us about the perspective of the patients towards palliative care. It gives an account of need of present situation of palliative care as well as expectations of patients from palliative care. From the present study, it is clear that geriatric population and cardiovascular disorders need palliative care most. In present study, some lacunae also exist. There is great scope for improvement in service and orientation towards palliative care. After all palliative care is meant for 'adding life to years and not years to life.'

KEYWORDS

Palliative care, Awareness, General population.

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BACKGROUND

Adequate symptom relief is a central aspect of medical care in all patients, especially those with incurable diseases.¹ Signs and symptoms of disease/disorder maybe relieved by medicines, but its aftereffects on physical and mental health should be properly taken care of. Sometimes, as disease progresses, palliation becomes the paramount goal of care.

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Here comes the role of palliative care/medicine. Palliative Care (PC) is defined as an approach that improves patients' quality of life 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.² Another authority defines it as patient and family centered care that optimises quality of life by anticipating, preventing and treating the suffering. This is another definition of PC has been put forth by clinical practice guidelines for quality palliative care under national consensus project for quality palliative care.³ Palliative care is an urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases. Palliative care is particularly needed in places where a high proportion of patients present in advanced stages and there

is little chance of cure. Ideally, palliative care services should be provided from the time of diagnosis of life-threatening illness, adapting to the increasing needs of cancer patients as the disease progresses into the terminal phase. They should also provide support to families in their bereavement.⁴ Palliative care includes provision of relief from pain and other distressing symptoms and support system to help patients live as actively as possible until death; affirmation of life and regards dying as a normal process; integration of the psychological and spiritual aspects of patient care; offering a support system to help the family cope during the patient’s illness and in their own bereavement; using a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; enhancing quality of life, and may also positively influence the course of illness. It is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life such as chemotherapy or radiation therapy. This also includes the investigations needed to better understand and manage distressing clinical complications.

As patients struggle to find closure in their lives, active listening and empathy have therapeutic value in and of themselves.⁵ There are many difficulties for the physicians, while delivering PC. Professionally too, the experience varies among physicians. Currently, most professional healthcare training barely addresses end of life care. Although, advances have been made in understanding the impact of death and loss, too little has been done to apply this knowledge in preparing healthcare professionals for the challenges of palliative care.⁶

In India too, non-communicable disease has become a major public health challenge and chronic disease accounts for 53% of all deaths and 44% of disability-adjusted life years lost.⁷

With a crude death rate in India of 6.24/1000 and a population of more than a billion and total number of people dying every year in India is about 7 million and the majority of them die in misery. According to the WHO estimates, more than 4 million people will benefit from palliative care. <1% of those who need palliative care services have any access to such services in the country.

AIMS AND OBJECTIVES

We have decided to dig in and look for the experience and scenario of patients towards PC. With the aims clarify the number of palliative care services and to obtain information regarding physician’s view about palliative care, we have conducted the study.

MATERIALS AND METHODS

A cross-sectional non-experimental survey design was used. The study has been conducted after approval from the institutional ethical committee. This is in line with Helsinki declaration. Sample size is calculated using % frequency of outcome factor in population (p) as 20%, confidence limit (r) as 5% and design effect as 1. Formula used was $4pq/r^2$ where q is 1-p. With this formula, the required sample size

comes out to be 256. Therefore, we have recruited 288 subjects by taking into account 5% dropouts. A simple random sampling method was used to recruit the subjects. Random numbers are generated from random number generator software available online. Participants were invited to participate via information tables, personal visits, telephonic and email invitations, hospital visits and personnel interview. They were given forms with predefined questionnaire. It was validated by three senior faculty members working in palliative care since last 20 years. They completed the questionnaire and returned to the investigators.

Data collection has been started in January 2017 and completed in June 2017. The survey involved different setups like private hospitals, government hospitals, private clinics, etc. Different setups were chose so as to avoid the bias towards palliative care practice. Patients from various categories are recruited to avoid selection bias and bias towards palliative care.

RESULTS

Among 288 patients who participated in study, 127 (44%) were females and 161 (56%) were males. The age group varied from 1 to 93 years in general population. Among the patients, 120 (42%) were from urban area, whereas 111 (38%) and 57 (20%) were from suburban and rural area, respectively. Patients enrolled were getting medical care facilities from 9% private clinic, 5% charitable hospital, 6% corporate hospital and 80% government hospital.

Age Group	Acute Disease	Chronic Disease	Total
Less than 15 years	14 (38%)	23 (62%)	37 (100%)
15 to 60 years	32 (15%)	176 (85%)	208 (100%)
More than 60 years	7 (16%)	36 (84%)	43 (100%)
Total	53 (18.4%)	235 (81.6%)	288 (100%)
Table Shows the Distribution of Disease from Which Patients were Suffering			

The number of visits required per month were <5 in 203 (70%), 5-10 in 66 (23%) and >10 in 19 (7%) of patients. The more frequent visits were seen in patients suffering from chronic diseases such as chronic kidney diseases, cancer and heart disease.

Awareness Regarding Palliative Care

Of 288 patients, 52 (18%) were aware regarding palliative care and 236 (82%) were unaware. Among the aware, 25 (48%) were aware of both home and center-based facilities. The awareness was mainly through medical personnel (73%). As an overall view, 78% patients felt that home PC is better than center based (22%). There was no statistical difference among the subgroup of patient form area in regarding awareness.

Knowledge regarding services offered and time to intervene (early/late) was very much inadequate in general population. Unfortunately, only 7% of general population opted to start palliative care early (immediately after the

diagnosis of terminally ill disease is made), whereas the majority of the population did not know about early intervention.

Most participants had a general knowledge of palliative care largely influenced by their own personal experience. They identified that palliative care was about caring for people who were dying and maintaining comfort in the last days of life. Participants' expectations of services included-holistic support, symptom management, good communication and practical support to enable choice and carer support, financial support for obtaining care and services. Figure 1 shows age-based need for palliative care.

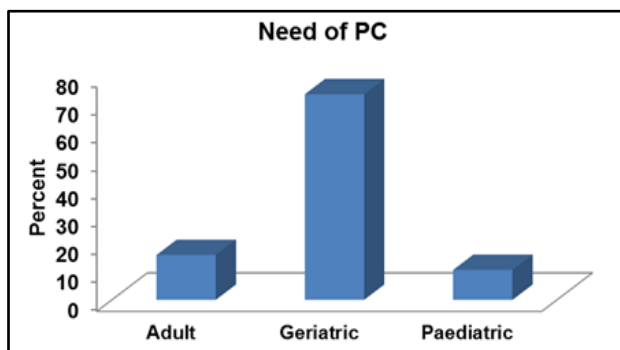


Figure 1. Need of PC as per Age

Figure 2 shows need of PC based on disease or system involved. Among the majors, Cardiovascular Diseases (CVDs) is leading one followed by central nervous disorders, respiratory system (COPD) and renal diseases (CKD).

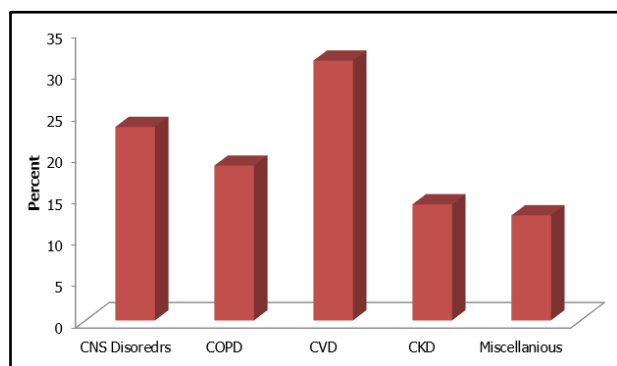


Figure 2. Need of PC Based on Disease

Among the patient obtaining PC when asked to rate overall experience with palliative care, 9% found it very dissatisfied, 31% were dissatisfied, 37% were neutral, while 12% were satisfied with it. Only 11% found it very satisfied. This means nearly 40% are aggrieved. This is shown in figure 3.

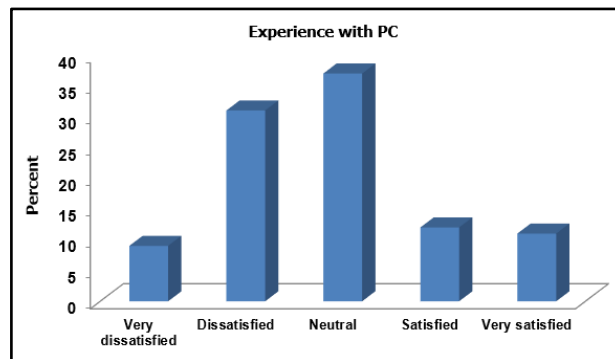


Figure 3. Experience of Patients with Palliative Care

DISCUSSION

There are very few studies in India with respect to palliative care and perspective of patients. Though there are some previous studies available, ours is one of the pioneering works to study this aspect. There is definitely the difference of opinion among the patient, but most of them feel that the need of palliative care is maximum for elderly people.

Populations worldwide are ageing leading to a dramatic increase in the numbers of people living into their 70s, 80s and 90s. Patterns of disease in the last years of life are also changing. Geriatric population is the one, which needs palliative care more as compared to adults and children. This is because, there are inherent problems of old age. Decreased immunity, regenerative capacity and increased wear and tear, irreparable damages are among the reasons, which are responsible for this. Mobility has also been decreased in the old age. At times, some or other psychological disturbances exist in this population. Loneliness is one of the major concerns among the elderly people. In last years of life, they have symptoms such as pain, anorexia, low mood, mental confusion, constipation, insomnia and problems with bladder and bowel control.⁸ Palliative care services urgently need to be developed to meet the complex needs of older people. In current situation, busy schedule of other family members also contribute to the loneliness. Elderly may therefore have palliative care needs at any point in the illness trajectory and not just the terminal phase. All these aspects probably lead physicians to think that elderly population requires the palliative care most.

Young population has relatively less health issues. In addition, it is noticed in society that paediatric population is provided with more attention and care. These might be the reason that very few children brought to physicians for palliative care. Palliative care guidelines that are appropriate for adults are often inappropriate for children.⁹ The provision of palliative care for children involves a partnership between the child, family, parents' employer(s), teachers, school staff and healthcare professionals, including nurses, chaplains, bereavement counsellors, social workers, primary care physicians, subspecialty physicians and consultants. Physical, emotional, psychosocial and spiritual/existential domains of distress must be addressed. The child should participate to the fullest extent possible, given his or her

illness experience, developmental capacities and level of consciousness.¹⁰

Among the organ systems, cardiovascular system is the most affected one. This is probably because there is more number of patients suffering from cardiovascular disorders than rest of the categories. Literature reports that many cardiovascular conditions present with emergency or acutely. A study observes that almost all chronic conditions start acutely, but demand prolonged treatment that may stop or slow down the disease progress.¹¹ As per 'burden of disease in India' by 'National Commission on Macroeconomics and Health - 2005', CVDs contribute 10% of all, while 31% in Noncommunicable Disease (NCD). In future, it is projected to have 53% share of NCDs.¹² This is followed by CNS disorders. CNS disorders are chronic disorders seen more in geriatric populations. There are various trajectories described for various group of patients. Three typical illness trajectories described are one for patients with progressive chronic illness- cancer, another for organ failure and the last is for frail elderly or dementia.¹³

Physical, social, psychological and spiritual needs of patients and their caretakers are likely to vary according to the trajectory they are following. Patients are usually ill for many months or years with occasional acute, often severe exacerbations. Deteriorations are generally associated with admission to hospital and intensive treatment.¹⁴

In the cases of neurological disorders, people who escape cancer and organ system failure are likely to die at an older age of either brain failure (such as Alzheimer's or other dementia) or generalised frailty of multiple body systems.¹⁵ This third trajectory is of progressive disability from an already low baseline of cognitive or physical functioning. Such patients may face weight loss and functional incapacity. They easily fall prey to trivial events and daily hassles. These events maybe routine, but in presence of decreased functional reserve and compromised overall capacity may become fatal.^{16,17}

When it comes to overall experience of the patients, majority of them are dissatisfied. This dissatisfaction is regarding provision of palliative care. There is very less knowledge about palliative care in the society. Not only layman, but also many doctors are not well aware of it. This shows the present situation of palliative care, which has great scope for improvement.

CONCLUSION

Present study tells us about the awareness and attitude of patients towards palliative care. It gives an account of need of present situation of palliative care as well as expectations of patients from palliative care. Not only, present scenario is made clear, but also the need of palliative care has also been elaborated. The disorders and systems involved as well as need of palliative care based on age group are also discussed. From the present study, it is clear that geriatric population and cardiovascular disorders need palliative care most. Last, but not the least is great scope for improvement in service and orientation in people towards palliative care.

After all, palliative care is meant for 'adding life to years and not years to life'.

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