

The Perspectives on Including Palliative Care in the Indian Undergraduate Physiotherapy Curriculum

ZUBIA VEQAR

ABSTRACT

According to the guidelines which were published by WHO in 2008, palliative care has been defined as “An approach that improves the quality of life of the patients and their families who face the problems which are associated with life-threatening illnesses, through the prevention and relief of suffering by means of an early identification, an impeccable assessment and the treatment of pain and other problems, physical, psychosocial and spiritual” . The intervention which is provided as a part of the palliative care has to be provided by health professionals who strictly work as a part of multidisciplinary team and have been specifically trained to an optimal level of competency in the field.

The impairment of the physical function and pain are two key problem areas in palliative care, which a physiotherapist deals with. Is a physiotherapist who is trained in India, trained to work as an efficient member of the team in this field?

This article deals with the following:

1. What is palliative care and what is its importance?
2. A multidisciplinary approach to palliative care
3. The scenario of palliative care in India
4. The role of physiotherapy in palliative care.
5. The current scenario of physiotherapy education vis a vis palliative care.

Key Words: Palliative care, Multidisciplinary approach, Physiotherapy, Physiotherapy education

INTRODUCTION

“We must all die. But that I can save him from days of torture, that is what I feel is my great and ever new privilege. Pain is a more terrible lord of mankind than even death itself.” Dr Albert Schweitzer, humanitarian, theologian, missionary and medical doctor, winner of the Nobel Peace Prize in 1952.

Palliative care is growing at a fast pace across the world, but millions are still not getting helped. This is because of the level of growth of this specialty in various regions of the world.

The economist intelligence unit was commissioned by the Lien Foundation (a Singaporean philanthropic organization) to devise a quality of death index to rank the countries according to their provisions of the end of life care. The index scored the countries across four categories-1. The basic end of the life healthcare environment 2. The cost of the end of life care 3. The availability of the end of life care and 4. The quality of the end of life care. India ranked the lowest in the overall score at 40th, whereas UK topped the list. India is 39th, 39th, 35th and 37th respectively in the four categories. If as a country, we are at one end of the spectrum, our own state, Kerala, has a special mention in the report for community care [1]. The low scoring of even the developed countries shows a poor quality and availability of care and a lack of policy coordination [1].

Palliative care is a multi disciplinary collaboration between the health care professionals, the patients and their families and the general public [2,3]. Derek Doyle clearly mentioned in his book that “No one professional can deal with the many problems which are encountered in palliative care.” The ideal core team which was proposed by him included a physiotherapist [3]. Keeping this in mind; it is our moral and ethical responsibility to educate our graduates to an acceptable level of competence in this sector of health delivery. Hence, this article is a humble step towards

analyzing our physiotherapy curriculum to understand whether we were making our physiotherapy graduates competent and responsible members of the palliative care team.

PALLIATIVE CARE

“You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you, not only to die peacefully, but also to live until you die”. – Dame Cicely Saunders, founder of the Hospice movement. The World Health Organization (WHO 2008) defined palliative care as a “An approach that improves the quality of life of the patients and their families who face the problems which are associated with life-threatening illnesses, through the prevention and relief of suffering by means of an early identification, an impeccable assessment and the treatment of pain and other problems, physical, psychosocial and spiritual” [4]. Palliative care is all about relieving suffering and achieving the best possible quality of life for the patients as well as their care givers [5]. All of this can be explained by one goal of helping the patients to die with dignity [6]. But this is not anyway, a support for euthanasia. The dignity which concerns care, offers an approach that clinicians can use to explicitly target the maintenance of dignity as a therapeutic objective and as a principle of bedside care for the patients who are nearing death [6].

This specialty is commonly also referred to as ‘low tech and high touch’. Palliative medicine became a medical specialty in the UK in 1987 [3] and other European countries followed suit. In India, it is still in its infancy, as far as the practice and the education goes. Organizations like the Indian Association of Palliative care, Palliative India and the Institute of Palliative Medicine are working with an increasing population of patients and they are also trying to popularize this field as a medical specialty [7].

The key features of palliative care

1. The palliative care goals and plans are based on the patient and not on the condition [3].
2. They are not related to the prolonging of life, but are related to the decrease of suffering (physical, psychological and existential) [3, 4, 8].
3. The caregivers and the patients, both are involved in the planning of the goals [4, 8].
4. It is a strictly multidisciplinary team which is called as the palliative care team [2, 3, 6, 7]
5. No member of the staff, junior or senior, should ever be expected to learn the basics of palliative care on the job [3].
6. It is appropriate for all the patients with an active, progressive, far advanced disease and not just for the patients with cancer [3,5,6].
7. It neither hastens nor postpones death [1,8].

Why is palliative care important?

For the first time, since the evolution of the Homo sapiens people over the age of 65 will outnumber children under the age of five. By 2030, the number of people who are aged 65 years or more is projected to reach 1 billion, which is 1/8th of the total population [1, 9,10]. This aging population will change the way in which people will die in times to come. The top five reasons of the mortality for 2020 are -heart diseases, CVD, chronic respiratory disease, respiratory infections and lung cancer [9].

A status report which was published by Billing et al., [10] suggested a number of reasons for the increased attention to palliative care in USA. They are:-

1. A growing interest in death and dying
2. The development of hospice programs and increasing their integration into the conventional care
3. Concerns about the high costs of dying
4. An increasing national focus on pain management
5. A greater attention to caring rather than curing
6. National debates on euthanasia and physician assisted suicides

A multidisciplinary approach

The patients come with various symptoms like pain, anorexia, constipation, etc hence, a multidisciplinary team is a must for an effective palliative care [3]. There is evidence that a multispecialty team in palliative care improves the satisfaction, that it identifies and deals with more family needs and that it decreases the cost of the treatment by decreasing the time which is spent in acute hospital settings [11].

An ideal multidisciplinary team consists of [1-6,12-14]:

1. Physicians / Surgeons
2. Nurses
3. Social Workers and
4. Physiotherapists

Some other members who are very useful but are not a part of the core team are:

1. Clinical psychologists
2. Clinical Pharmacists
3. Music and /or art therapists and
4. Occupational therapists

According to the prescribed guidelines, an IPD Unit which has more than 15 beds needs a physiotherapist (PT) on staff and one which caters to more than 30 beds needs a full time PT [3].

The Basic Aims of the Management of a Palliative care Multi Disciplinary team are:

1. To gain the confidence of the patient
2. To ensure that the patient understands the concept of dying with dignity.
3. To manage pain and other physical symptoms.
4. To improve the patients' QOL within the available conditions.
5. To provide the patients with psychological, sociological and spiritual care.
6. To provide support and help to the caregivers.

Palliative care in India

In India, which has a population of 1.22 billion (2012 census), the life expectancy at birth is 66.8(2012 census) years .There is a tremendous burden of the disease but the access to and the availability of the health care delivery system is very poor. Lately, the explosion of cancer and AIDS in India has made the requirement of palliative care even more acute. The exact requirement of palliative care is difficult to calculate because of a lack of registration, a lack of communication and cultural and social stigmas, which go with the diagnosis of AIDS and cancer [15]. Approximately 52 million people die each year [3] and more than 7 million people with life limiting illnesses may need palliative care in India every year [16]. These patients are living everyday with pain which can be relieved, uncontrolled physical symptoms which can be controlled and uncontrolled psychological and social trauma which can be managed [3,6,17].

A traditional form palliative care has been practised in India since ancient times, through a home based spiritual and religious care of the dying according to traditional customs and rituals. A significant progress with palliative care has been made in India, with the integration of palliative care in major cancer centres and with the offering of fellowships in palliative medicine [14] but it is still in the stage of infancy. Over the past 30 years, there has been a growing awareness in the Indian population (among specialists as well as general physicians) regarding palliative care. It originated in Kerala (1986) with the starting of the pain clinic in the Regional Cancer Centre of Trivandrum [14]. The first western style palliative care patient unit was started as the Samvedna Ashram (1986) in Mumbai.138 hospice and palliative care services in 16 states and UTs are being currently offered in India [18] Kerala is the only state which is offering palliative care services in all the districts and it was the first state which declared its palliative policy in 2008 [11,14,16,18].

The models of delivery of palliative care in India

1. **Inpatient care units:** These are the dedicated inpatient units. The first was the Samvedna ashram in Mumbai, followed by many others like the Samvedna ashrams in Goa and Delhi. These units suffered from a low bed occupancy initially, they but soon got filled up. They became very important, especially because they filled up the lack of social security somewhere, by providing free services to the poor and the destitute and by removing the social stigma of being diagnosed with a terminal illness [14,15,18].
2. **Government regional cancer centres:** Since the adoption of palliative care in cancer support, a few centres have been started, with palliative care units. The first was started in Trivandrum. There are 11 centres throughout the country which are offering these services [15].

3. **Domiciliary services:** These are services which cater to the patients at their homes. This is because a number of patients would like to die in the familiar surroundings of their homes [18]. These kinds of services are run with the help of volunteers and specialists. Volunteers doing the job of nurses might seem unethical, but it is justifiable because of the lack of trained professional in India. These kinds of services can be seen in Delhi, Bangalore and Kerala [15].
4. **Combined inpatient and training centres:** The Cipla Palliative Care and Training Centre was started in Pune, India by the pharmaceutical giant, Cipla, as a project of community service, where the patients are kept for a short period and their caregivers are trained to take care of them during this period, thus making them self reliant [15].

The government policies regarding palliative care are very patchy. The centre and state government policies have been discussed here briefly:-

Central government policies: India has no national palliative care policy [16]. In 2005, a task force was formed by the Ministry of Health and Family Welfare, which submitted this recommendation in 2006. It proposed certain steps which had to be taken by the government. They are:

1. Policy – Include palliative care in the national and state policies.
2. Palliative care service development
3. Opioid availability
4. Education and Training palliative care and
5. Advocacy, awareness building and community participation at the state level.

State government policies: Most of the state governments have played little or no roles in the development of palliative care. The Kerala government is the only state government with a palliative care policy [15].

According to the Human Right Watch, the common barriers in the way of the access to the palliative care in India, have been identified as:-

1. A lack of services in most parts of the country
2. A lack of awareness among professionals, administrators and the public in general
3. A lack of facilities for palliative care education in the country
4. Unrealistic narcotic regulation. and
5. A lack of clear guidelines for those who wish to provide palliative care services.

In our neighbouring country, Pakistan, there are two known hospices, they are both run by private charities and they have a long way to go [19].

The Role of Physiotherapy in Palliative care

A physician adds years to the life and a physiotherapist adds life to the years. WCPT defines it as “A physical therapy which provides services to individuals and population to develop maintain and restore the maximum movement and functional ability throughout the lifespan”. This includes, providing services in circumstances where the movement and function are threatened by aging, injury, diseases, disorders, conditions or environmental factors. Functional movement is central to what it means to be healthy. Physiotherapy is concerned with identifying and maximising the quality of life and the movement potential within the spheres of promotion,

prevention, treatment/intervention, habilitation and rehabilitation. This encompasses the physical, psychological, emotional, and the social wellbeing. Physiotherapy involves the interaction between the PT, patients/clients, other health professionals, families, care givers and communities, in a process where the movement potential is assessed and goals are agreed upon, by using the knowledge and the skills which are unique to the PT [20]. A pain free movement is one of the core principles of improving the quality of life. A reduction in the pain without physiotherapy is difficult to perceive. A PT's intervention in palliative care started as early as in the 1960s [21-22], which was before the commencement of the modern hospice movement. But today, the scenario has changed. Laakso et al., concluded that an early PT intervention, followed by a community follow up, improved the maintenance of the functional independence and the quality of life of the patients who received palliative care [22] The patients who receive palliative care experience high levels of functional disability which are related to the disease progression, deconditioning, pain, incontinence, respiratory dysfunction, direct tumour affect and paraneoplastic syndromes or local or systemic effects of the cancer treatment and its complications [7,13,22-25]. A decrease in the level of function is one of the major concerns in the decrease of the quality of life of the patients and regaining the functionality is one of the major goals for the patients [23]. As has been described by Laakso [22], a PT intervention in palliative care works at four levels.

1. **Prevention:** plans to educate the family and the patient, large muscle group strengthening, etc.
2. **Pre and post operative care:** back to activity as soon as possible, recovery of the respiratory function, etc.
3. **An acute institutional and community based rehabilitation:** by teaching mobility techniques, making the patient independent, etc.
4. **Palliative care:** pain management, symptom control, etc

Toot said that a PT plays the role of a clinician by delivering a direct patient care and an educator by providing education to the patient family care unit and fellow health professionals and team members by communicating effectively, facilitating a team interaction and innovating extemporaneously [13]. Kumar et al., [20] stated that PT aims to:

1. Maintain an optimum respiratory function
2. Maintain optimum circulatory functions
3. Prevent muscular atrophy
4. Prevent muscle shortening
5. Prevent joint contracture
6. Influence the pain control
7. Improve the mobility of the patient.
8. Improve the quality of life of the patient.
9. Improve the functional independence.
10. Educate about and participate in the care.

A report which was submitted by Teed and Kepling (2009) mentioned about a review on the effects of physiotherapy on the patients with cancer in palliative care settings. They concluded that physiotherapy can play a very important role in enabling the independence and promoting the health in patients with terminal illnesses [4].

A PT can use various interventions like electrotherapy, manual therapy, mechanical therapy, exercise therapy, etc, to gain the desired effects.

The Current Levels of education in Palliative Care in The Undergraduate Physiotherapy Curriculum

Various government and private universities are offering courses of physiotherapy throughout India. The various levels of study have been listed as below:

1. **Diploma in Physiotherapy (DPT):** e.g by Aligarh Muslim University. The duration of the course is 3 years with six months of compulsory internship.
2. **Bachelor of Physiotherapy (BPT/BPTh):** e.g. by Jamia Millia Islamia, Maharashtra Health University, Amity University, Jamia Hamdard etc. The duration of the course is 4 years with 6 months of compulsory internship.
3. **Masters in Physiotherapy(MPT/ MPTh):** e.g by Jamia Millia Islamia, Jamia Hamdard, Maharashtra Health University, Manipal University, etc. Various specialties like orthopaedics, neurosciences, cardiopulmonary, sports, etc are being offered. The course duration varies from 2-3 years.
4. **Doctor in Philosophy (PhD):** e.g. by Jamia Millia Islamia, Guru Nanak Dev University, etc.

The importance of education in developing the palliative care programme cannot be overemphasized. This was one of the recommendations of the WHO too. The importance of palliative care in the undergraduate curriculum of health professions has been well documented in the western literature [26-30] and it is a part of their undergraduate curriculum worldwide. The introduction of palliative care in the undergraduate medical and nursing training in the western countries have paved way to introduce palliative care into the Indian medical and nursing curriculum. St.John's National Academy of Health Sciences was the first institute to introduce palliative care into the undergraduate medical and nursing curricula. This has been a major step towards the development of a formal system of education and the implementation of palliative care in India, but we are still lagging far behind. Sadhu et al., reported the unpreparedness and the lack of expertise in the death and dying and the end of life care issues among our undergraduate medical, nursing and allied health students [31]. They concluded in their study that:

1. There is a lack of understanding on palliative care in India
2. There is an urgent need to include palliative care in the undergraduate curriculum of health professionals.
3. A focused training in palliative care can bring about a positive change eventually.

Dealing with patients in the palliative care units is a challenge for the physiotherapy students who have to overcome a sense of despair at the inability to heal or restore optimal functional levels. This becomes all the more difficult if they are not trained to handle such cases. Keeping in mind the growth in the field and the necessity in the society, this course must be added to the undergraduate physiotherapy curriculum, preferably in the final year. This course will not only equip them to handle the patients in palliative care setups, but it will also teach them the importance of support and strategic planning for those with terminal illnesses and in bereavement management.

As far as the physiotherapy curriculum in India is concerned, an course on palliative care has not offered in any university at the undergraduate level, to the best of my knowledge. However, it may be added that physiotherapy in oncology has been offered as a subtopic in PT in general medicine, in a few universities. After going through the literature, I would strongly like to recommend that a course on undergraduate curriculum.

CONCLUSION

Palliative care is a very important branch of medicine but it is a thoroughly neglected area in the medical and allied health practice and in the education in India. Physiotherapists play a very important role in the multidisciplinary team of palliative care. A course on palliative care must be added at the undergraduate level of the physiotherapy education.

REFERENCES

- [1] Economist intelligence unit. The quality of death: ranking end- of- life care across the world, 20010[cited 2012 April]. Available from graphics.eiu.com/upload /QOD_main_ final_ edition_ Jul12_ to print.pdf .
- [2] Kumar SP, Jim A, Sisodia V. Effects of Palliative care training program on knowledge, attitude, beliefs and experiences among students physiotherapists: A preliminary quasi experimental study. *Indian J Pall Care* 2011 ;17(1);47-53.
- [3] Doye D, Getting started guideline and suggestions for those starting a hospice/Palliative care service[Internet]. IAHPHC press Houston 2009 2 edition [cited 2012 April 10] available from www.hospicecare.com/gs/book/IAHPHC_Getting_Started_2nd_ed.pdf .
- [4] Teed R, Keating J. Palliative care education in Australian physiotherapy undergraduate curricula;2009 [cited 2012 April 11] available from www. caresearch.com.au /caresearch /linkclick.aspx?fileticket=DWOXAKlpq6=&tabid=1695.
- [5] Chochinov HM. dignity- conserving – A new model for Palliative care helping the patient feel valued. *JAMA* 2002; 287(17); 2253-60.
- [6] Mackey KM, Sparling JW. Experiences of older women with cancer receiving hospice care :significance for physical therapy. *PhysTher*. 2000; 80(5);459-68.
- [7] Elizabeth D, Higginson IJ. The solid facts – Palliative care. WHO 2004. [cited 10 April 2012]available from www.euro.who.int /data/assets/pdf_file/0003/98418/E82931.pdf.
- [8] Kulkarni PD. Hospital – based Palliative care : A case for integrating care with cure. *Indian J Pall Care* 2011;17(suppl); S74-576.
- [9] Billings JA, Block S. Palliative care in undergraduate medical education. *JAMA* 1997;278(9);733-38.
- [10] Hearn J, Higginson IJ. Do specialist Palliative care teams improve outcome for cancer patients ? A systematic literature review. *Palliat Med* 1998; 12 ;317-32.
- [11] Hanneke DH ,Saskia T. Communication in Palliative care : a review of recent literature. *Current Opinion in Oncology* 2005; 17(4);345-50.
- [12] Toot J. Physical therapy and hospice – concept and practice. *PhyThr* 1984;64(5);665-71.
- [13] Mudignonda T, Mudigonda P. Palliative cancer care ethics: principles and challenges in the Indian setting. *Indian J Pall Care* 2010;16(3); 107-10.
- [14] Seamark D , Ajitha Kumari K, Burn G, Devi PS, Koshy R, Seamark C. Palliative care in India. *J R Soc Med* 2000;93 ; 292-95.
- [15] Human rights watch. Unbearable pain- India obligation to ensure Palliatvecare .October 2009[cited 10 April 2012] Available from www.hroo.org/sites/default/files/reports/health 1009web.pdf.
- [16] Palliative care Australia [internet]. Australian dying badly(Media release); 5nov 2009[cited 11 April 2012] available from www.palliatvecare.org.au/Portals/46/media/Australians%20Badly%20-%20PCA%Release%205%20Nov%20 2009.pdf .
- [17] Chaturvedi SK. Ethical Dilemmas in Palliative care in traditional Developing Societies, with special reference to the Indian Setting. *J Med Ethics*. 2008;34;611-15.
- [18] MeghaniSH , Aziz Z. The need for an Effective Palliative care strategy in Pakistan [Letter] *Journal of Public Health Policy* 2008;29;480-84.
- [19] Kumar SP, Jim A .Physical therapy in Palliative care : From symptom control to Quality of life: A critical review. *Indian J Pall Care* 2010; 16(3): 138-46.
- [20] Dietz H. Rehabilitation of the cancer patient. *Med Cl North Am* 1969;53: 607-24.
- [21] Laakso L. The role of Physiotherapy in Palliative care. *Aus Family Physician* 2006;35(10):781.
- [22] Montagnini M, Lodhi M, Born W. The utilization of physical therapy in a Palliative care unit. *J of Pall Med* 2003;6(1):11-17.
- [23] Kumar SP. Cancer pain: A critical review of mechanism – based classification and physical therapy Management in Palliative care. *Indian J Pall Care* 2011; 17(2): 116-26.
- [24] Breden K. Teaching Palliative care across cultures: the Singapore experience. *Indian J Pall care*. 2011; suppl:s23-s25.

- [25] Billings JA, Block S. Palliative care in undergraduate medical education. *JAMA* 1997;278(9):733-73.
- [26] Lloyd- Williams M, Macleod RD. A Systematic review of teaching and learning in palliative care within the medical undergraduate curriculum. *Med Teach* 2004;26(8):683-90.
- [27] Franks AL. Teaching medical undergraduates basic clinical skills in hospice—is it practical? *Postgrad Med J* 2000;76:357-60.
- [28] Field D ,Wee B. Preparation for Palliative care: teaching about death, dying and bereavement in UK medical schools 2000-2005 *Med Educ* 2002;36:561-67.
- [29] Gibbins J, MC Coubrie R, Fordes K. Why are newly qualified doctors unprepared to care for patient at the end life? *Med Educ* 2011;45: 389-99.
- [30] Gibbins J, MC Coubrie R, Forbes K. Incorporating palliative care with undergraduate curricula: lessons for curriculum development. *Med Educ* 2009;43:776-83.
- [31] Sadhu S, Salins NV, Kamath A. Palliative care awareness among Indian undergraduate health care students: A needs-Assessment study to determine incorporation of palliative care education in undergraduate medical, nursing and allied health education. *Indian J Pall Care* 2010; 16(3): 154-59.

AUTHOR(S):

1. Dr. Zubia Veqar

PARTICULARS OF CONTRIBUTORS:

1. Assistant Professor,
Centre for Physiotherapy and Rehabilitation Sciences,
Jamia Millia Islamia, New Delhi, India.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:

Dr. Zubia Veqar,
Assistant Professor,
Centre for Physiotherapy and Rehabilitation Sciences,
Jamia Millia Islamia, New Delhi, India.
Phone: 0091-9958993486
E-mail: Veqar.zubia@gmail.com

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