### Perspective

### Inclusion of Palliative Care in Indian Undergraduate Physiotherapy Curriculum-course Guidelines and Content

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#### ABSTRACT

According to the guidelines published by the WHO in 2010, palliative care has been defined as "an approach that improves the quality of life of patients and their families facing the problem 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." Intervention provided as a part of the palliative care has to be by health professionals who strictly work as a part of the multidisciplinary team and have been specifically trained to an optimal level of competency in the field. Two key problem areas in palliative care

which a physiotherapist deals with are poor physical function and pain. This article deals with the following issues: (1) What is palliative care education and its importance? (2) Current scenario of palliative care in medical and allied fields internationally. (3) Current scenario of palliative care education in medical and allied fields in India. (4) Proposed curriculum guidelines for palliative care in physiotherapy.

**Key words:** Curriculum, multidisciplinary approach, palliative care, physiotherapy, education

#### Introduction

Palliative care is the care imparted to a patient where long-term control or cure is not a primary goal. The primary goal here is to allow the patient to have a decent quality of life (QoL) within the existing

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limitations. The first documentation of the concept of palliative care can be dated back to the crusades where similar services were provided by the religious orders. Eventually, by 1960s medical professionals had realized that a lot of the pain and suffering which

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terminally ill patients undergo can be managed. Hence, the hospices and palliative care services were started. [1]

Palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problem 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" by the WHO (2010).[2] It describes the importance of palliative care and its various aspects. It emphasizes the fact that palliative care is about the patient as well as the caregivers.[3] Patient comes with a multitude of symptoms. Hence, the multidisciplinary team is a must for an effective management with physiotherapist being an essential part of the team. [4] Physiotherapy management in palliative care aims to provide complete comfort to the patient (within permissible range) while maintaining high level of physical mobility as the condition progresses. The United Kingdom was the first country to recognize palliative care as a medical specialty and soon other European countries followed suit.[4]

India is a country with the second highest population in the world, but only a handful of around 1% have an easy access to palliative care. [5] Even though modern-day palliative care model is fairly new in India, home-based holistic care of dying can be traced back to ancient times. This home-based care was based on traditions and religious beliefs which were considered to be both ethically as well as morally correct. Pain is generally accepted in all religions as atonement. The palliative care facilities in India were established in around the early 90s to provide palliative care within the existing cancer centers were in some places such as Ahmedabad, Bengaluru, Mumbai, Trivandrum, and New Delhi. There is a presence of 139 hospices in the whole of the country as reported in the literature out of which 83 are in Kerala. [6] The three main areas where improvement is recommended<sup>[5]</sup> by Rajagopal are enumerated as follows:

- 1. Implementation of the Narcotic Drugs and Psychotropic Substances Amendment act by all the 29 states 6 union territories to make the availability of drugs easier.
- 2. The Medical Council of India and the Indian Nursing Council have to incorporate palliative care education in the national curriculum as per Supreme Court of India guidelines.
- 3. National program has to be implemented by the states with appropriate budget allocation.

# **Role of Physiotherapy in Palliative Care**

In today's times, the role of a physiotherapist is varied and is much more evidence-based improved medical care in palliative medicine has prolonged the life of the patient, but a large number of them suffer from functional as well as other impairments which are due to the condition or a part and parcel of the treatment itself.<sup>[7]</sup> The poor physical function is also one of the major implications of poor QoL of the patient. Early rehabilitation during critical care stay improves physical function and hence leads to an early discharge. However, not all the critical care stay patients had been rehabilitated early. The role of early physiotherapy cannot be overemphasized. [3,7] Advancements in modern medicine have led to the longevity of the patient but it is also juxtaposed with chronic functional impairments. This aspect makes the role of physiotherapist very important in the effective management of a patient.<sup>[7,8]</sup>

Physiotherapy treatment can be divided into two phases: (1) The initial condition-specific phase where the management is focused on the condition. In this phase, the primary aims are to prolong life and improve the QoL.<sup>[7,8]</sup> (2) Late phase where the treatment is focused on the residual symptoms and the goals now shift toward improving the patient's QoL.<sup>[8]</sup> The goals of physiotherapy management are summarized<sup>[7,8]</sup> as follows:

- To maintain and restore mobility and function
- To maintain and restore skin integrity
- To maintain and restore cardiorespiratory functions
- To maintain and restore the appropriate functioning of the musculoskeletal system
- To prevent any vascular complications
- To manage pain as much as possible
- To manage and minimize fatigue
- To achieve maximum possible function
- Patient and family education

#### **Palliative Care Education**

Because it is a multidisciplinary teamwork, all the members of the team need to be well trained to give the best to the patient. Physiotherapist is an important part of the team. Hence, their curriculum should be dealt with this issue. This can be taught as a part of a subject or as a different subject at the undergraduate level. [9] The subsequent article will be dealing with this.

According to the recommendations of the WHO for palliative care development, any palliative care policy has to address:

- 1. Education
- 2. Drug availability
- 3. Policy

The first thing mentioned here is education thus the importance of education cannot be overemphasized. Education can be imparted at various levels and to different people, for example, the caregiver, the community, etc., and as few hour, few days, a few months, or as a subject in the regular education. All the members of the multidisciplinary team should be ready to answer all the questions by the support groups, caregivers, or the other members of the team. The purpose of the multidisciplinary team was not to overwhelm the patient family care unit with a swarm of professionals but to provide support when and where needed. Every team member needs to be educated enough to handle his/her job well.<sup>[1,10]</sup>

## **International Scenario of Palliative Care Education**

The need to introduce palliative care in undergraduate curriculum is strongly supported throughout the literature.[10-16] Palliative care is now considered in undergraduate medical, nursery, and physiotherapy training in many Western countries.[3,9-12,17,18] Great Britain is one of the countries where palliative medicine is a specialty and accordingly curriculum is designed too. There are quite a few published articles on palliative care education in undergraduate medical and nursing schools and they all agree that palliative care education has to be included in the undergraduate curriculum.[10-20] According to Hillier and Wee, [17] palliative care learning should be initiated at the undergraduate level. They also endorse the idea that all healthcare professionals must have some education in palliative care. To accomplish this goal, various methods of incorporation have been proposed such as practical training in the hospital care, practical and theoretical training, workshop, case presentations.[10-12,14-16]

There has been an increased emphasis on education in palliative care but the junior doctors are not able to correlate their acquired knowledge with the clinical practice<sup>[16,18]</sup> which would again start the debate on timing, content, and methodology to teach palliative care. Hence, there exist lacunae in the manner in which education is being currently imparted. The review published

by Lloyd-Williams and MacLeod further prove the point by suggesting that there is very little consistency in what medical undergraduates are taught and whatever taught is in an ad-hoc manner and is rarely assessed. [12] This is further supported by Gibbins et al.'s[16] recent publication where they have reported that the curriculum time and incorporation of learning objectives are the major challenges for the subject. There is a dearth of suitable patients and direct patient exposure is required for the basic skill teaching in palliative care.[13] The other methods reported in the literature are seminars/small group discussions, role play, clinical case discussions, visits, lecture, video/film, patients being used as teachers, and simulated patients.[14] Curriculum content of entry level programs for health professionals might include a basic understanding of palliative care principles, appropriate intervention, planning and assessment and the roles of the spectrum of health professionals.[3]

No research articles on curriculum or curriculum guidelines for palliative care in physiotherapy were found in literature pertaining to India even though a few articles on medical and nursing education were found. Teed and Keating have compiled an extensive report on Palliative Care Education in Australian physiotherapy undergraduate curricula<sup>[3]</sup> where they reported lack of evidence pertaining to palliative care physiotherapy education. At the end of the report, they have provided teaching, learning objectives, and the methods to achieve the same.<sup>[3]</sup>

## Scenario of Palliative Care Education in India

An internet search pointed out to a few studies which have been published in India regarding palliative care education of medical interns, nurses, and allied health professionals. [20-24] Palliative Care Training in India is almost nonexistent in most of Healthcare Training Program curriculums.[10,20,22] St. John's National Academy of Health Sciences was the first institute where palliative care was added to the undergraduate medical and nursing curriculum in 2001.[20] Sadhu et al.[21] studied palliative care awareness among Indian undergraduate healthcare students of medicine, nursing, and allied health education. They reported that Indian students were unprepared and had lack expertise in death and dying and end of life care issues because Health Care Training Programs including those training doctors who care for many dying patients fail to hold them accountable for competency in these areas. They gave three very important findings pertaining to Palliative Care in India:

- 1. Understanding of palliative care is deficient.
- 2. Palliative care has to be integrated at the level of health care education.
- 3. Focused training in palliative care can bring a reform in palliative care. [21]

The theoretical knowledge of palliative care concepts was better than the level of confidence in performing practical aspects of palliative care and the interns did not outperform the students in their overall performance. [23] The need of a structured approach and an integrated course curriculum involving principles of both primary and palliative care principles in improving the efficiency of undergraduate medical education was also emphasized by Valsangkar *et al.* [22] The need for education exists across clinical settings around the world. An improvement in the education system is an urgent need as the prevalence of cancer, AIDS, etc. is increasing and the burden is largely carried by the developing world where resources are limited. [24,25]

### Proposed Curriculum of "Physiotherapy in Palliative Care"

To the best of my knowledge, no paper has been published on curriculum designing or education in palliative care in physiotherapy in India though a few articles are available on medical and nursing schools. Veqar has discussed the importance of palliative care education in physiotherapy curriculum.<sup>[9]</sup> In Indian literature one article was found which compared nursing, medical, and allied profession (physiotherapy and occupational therapy) students in their understanding of palliative care<sup>[26]</sup> and one was to find out the effect of a short-term training course of palliative care on physiotherapy graduates.<sup>[20]</sup> There are a few studies which have reported specific condition awareness etc., such as cancer and AIDS<sup>[27,28]</sup> but not much has been reported on intervention and outcome measures. There are no randomized control trials reported from India on palliative care.

People with terminal illness pose challenge to physiotherapy students who have to overcome a sense of futility associated with palliative care that will not heal or restore to full health. Hence the education approach has to take care of the social denial of death and special sense of immortality that goes with the youth. It is required to transition students to a platform from which they can see the importance of support and strategic planning for those with terminal illness.<sup>[3]</sup>

Curriculum designing of palliative care in physiotherapy has to cover numerous issues and avoiding overlap will be a challenge. Basic knowledge about various conditions is a must before starting with the subject which automatically shifts it to the last year of teaching. This article has to use a two-pronged approach - attitude and content. Students have to learn to deal with the issue of dying and death and also understand the way the society deals with it. This course should be designed keeping in mind the following suggestions given by Billings and Block:<sup>[11]</sup>

- 1. An appreciation by the student of his own death
- 2. An appreciation of what it is like to be dying
- 3. An appreciation of the needs of the family members
- 4. An appreciation of the roles of other personnel, and further how those roles may be affected by the patient's death
- 5. The cultural aspects of dying and death. [2-9]

The importance of attitude and cultural issues cannot be overstated. [20,21,25,29] Pain and its expression, concepts of suffering and death and the acceptance of death all have cultural connotations. Thus, understanding of sociology and psychology becomes very valuable. It will be preferred that these subjects should have been completed before the commencement of physiotherapy in palliative care.

Forbes suggested the following principles in developing the curriculum of palliative care:

- 1. Knowledge imparted should be to relevant and only essential core information should be imparted.
- 2. Emphasis should be placed on smaller-sized groups so that a more effective approach of problem-based learning can be used.
- 3. The practice is multidisciplinary, so the education should also be the same.
- 4. All the team members of the multidisciplinary team and patients should be used as educators.
- 5. Teaching should be integrated.
- 6. Allow the student to ponder over.
- 7. Assessment should be done not only of the student only but also of the teaching and assessment methodology. [12,29]

This article further emphasizes on the importance of communication, selection of teachers, advantage of small group teaching and problem-based learning. [29]

I would like to suggest the following course objectives: [1,2,29]

- 1. The student should be able to understand the concept of palliative care.
- 2. The student should understand and learn strategies to manage grief.
- 3. The student should learn pain management.
- 4. The student should learn symptom management.
- 5. The patient should learn support care.
- 6. The student should learn effective communication at all times.
- 7. The student should learn to work as a part of multidisciplinary team.

The suggested syllabus is:

#### Introduction to palliative care

- What is palliative care?
- What are the concepts of hospice care, terminal illness/care, end of life care?
- The concept of dying with dignity
- Various models of delivery
- Understanding that goals of treatment will be different.

#### Ethics of palliative care

- Importance of the patient as self
- Importance of patient's choices
- Euthanasia and other such issues of terminal illness

#### Bereavement/grief

- · Normal and abnormal grief reactions
- · Issues of the grieving family
- Issues of the grieving patient
- · Management of the grief

#### Psychological and social issues

- Differences in patient's attitude toward illness
- Differences in patients attitude toward death
- Differences in family's attitude toward illness and death
- Importance of support systems in managing terminal illness
- Identifying common needs and preferences of patients with terminal illness
- Managing denial, anger, and crying
- Managing wrong attitudes and beliefs

#### **Communication skills**

- Importance of communication
- Importance of active learning
- Methods of effective communication with patients with terminal illness
- Methods of effective communication with patients family and caregivers
- Methods of effective communication within multidisciplinary team
- Methods of effective communication with the general population for awareness

#### Pain and physical symptoms management

- Philosophy and anatomy of pain
- Types and mechanism of pain
- Assessment of pain and its various tools
- · General principles of pain management
- Various physiotherapeutic methods of pain management

- Role of opoid, nonopoid, and nonsteroidal anti-inflammatory drugs
- The need of symptom controls in illness
- Treating comorbidities
- · Respiratory physiotherapy
- Exercise principles in palliative care

#### Physiotherapy in oncology

- Introduction to tumors types, pathology, staging, conservative, and surgical management
- Management of cancer pain
- Preoperative assessment and management of important tumors
- Postoperative management of important tumors
- Managing the complications of conservative management

#### Palliative management in other conditions

- Neurodegenerative disorders
- Spinal cord and brain injury
- · Critical illness
- Respiratory diseases
- AIDS and HIV-positive patients
- Psychiatric disorders

#### Multidisciplinary team

- Members of the team
- Role of each member of the team
- Principles of working in a team

#### Other ways of managing

- Music/drama/art, etc., in treatment
- Vocational support
- Spiritual well-being

The topics suggested are only brief guidelines. The number of hours allocated to the subject will depend on the year/semester in which it is added. This is because prior knowledge will decide the depth required. The subject should be taught by a multidisciplinary team. It is important that the faculty members have a background of working in palliative care.

Teaching methodology should include the following:

- 1. Lectures
- 2. Practicals
- 3. Role play
- 4. Case study discussion
- 5. Seminars/group discussion
- 6. Visit/training in P.C. units

The subject suggested is not a subtopic of a certain broader subject but as a separate entity which has to be taught throughout the year/semester with adequate practical training.

#### Conclusion

Physiotherapist plays a very important role in palliative care which has been appropriately emphasized throughout the literature. There is a dearth of literature pertaining to the role of physiotherapy in palliative care as well as its education vis-à-vis India. The presence of this subject is not felt in the existing curriculum of physiotherapy in India. This article is a small step toward visualizing the need and proposing guidelines for the teaching of this subject. Moreover it is also emphasized that this should be taught separately instead of as a part of a larger subject. This article suggests a guideline to curriculum designing in physiotherapy in palliative care.

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