

Palliative Care in Nursing - Where are we in Pakistan?

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Abstract

Palliative care is an integral component of cancer care. Developing countries like Pakistan are still struggling with the initiation and implementation of WHO pillars for establishing palliative care services. In Pakistan palliative care is a low priority issue with many other competing health and developmental issues. With the rising rates of cancer incidence, the national cancer plan was initiated in 2002, but the progress is very slow. This article focuses on the availability of palliative care services to population with special focal point on nursing training and education. The article reviews in depth the present curriculums of nursing education on palliative care. As per authors knowledge there is no existing graduate or undergraduate level of structured program. There has been no discussion in Pakistan nursing council, the licensure body in Pakistan to develop comprehensive curriculum for palliative care nursing. The empowerment process of Pakistani nurses to become active palliative care nurses begins with education and knowledge enhancement. Considering the present scope of palliative care there is an immense need of training, teaching and structured services in Pakistan.

Keywords: Palliative care nursing; Palliative care; Pakistan education

Introduction

Palliative care is considered an integral component of cancer care and WHO has urged countries to develop policies geared towards ensuring adequate drug availability, education at a national level and implementation of palliative care services at all levels [1,2]. However, in many developing countries, oncology services are quite neglected and the facilities available are not sufficient to take care of the needs of the population.

The key to managing palliative care includes provision of accessibility to all those who require palliative care, early diagnosis and treatment, provision of holistic care for the patients as well as their families to improve quality of life, and availability of resources required to provide end of life care throughout the country [3].

It is estimated that only one in 10 people who need palliative care are currently receiving it; 4 and only 2% of terminally ill patients having access to opioids to manage pain [1]. Almost 80% of the global need for palliative care is in low- and middle- income countries [4]. Despite its importance, by 2011, only 20 countries globally had managed to accomplish integrating advanced palliative care into their health services which included provision of all types of palliative care by multiple service providers, as well as broad awareness of palliative care by not only health professionals but society in general. These countries labelled category 4b have also managed unrestricted availability of morphine and have integrated public health policy into

its medical curriculum. Majority of these countries also have a very high human development index and can be considered the gold standard for palliative care integration and human development [5].

The purpose of this paper is to provide an overview of the current status of nursing in palliative care in Pakistan, including training, teaching and structured services available.

Pakistan scenario

Pakistan is located in Southern Asia bordering the Arabian Sea. It is situated between India on the east, Iran and Afghanistan on the west and China in the north. It is the 6th most populous country with an estimated population of 185 million with an annual population growth rate of 1.46% [6]. The age structure observed is that of a developing country with the 0-14 years constituting 32.65% of the population. The 15-64 years group forms the bulk of the population, i.e. 63% and the 65+ years comprising 4.35% of the population [7]. Pakistan is a low- to middle-income country ranking 146 out of 167 countries in UN's Human Development Index.

During the last decade, even though Pakistan's health burden has had a shift from communicable to non-communicable diseases, our health systems still lag behind and have not transitioned from disease-oriented to primary care and prevention-oriented [8,9]. In 2012, an estimated 148,000 people were diagnosed with cancer in Pakistan [10]. The largest city in Pakistan, Karachi, reported one of the highest incidences for breast cancer in any Asian population with the majority presenting with advanced disease [11].

In 2012, age-standardized cancer incidence rate of Pakistan was estimated at 111.8 per 100,000 people/year with approximately 101,000 persons dying of cancer per year [10]. Given this, the need for palliative care services in Pakistan cannot be ignored since the majority of patients present to health care facilities with an advanced stage of cancer and require palliation from the beginning.

Despite a large cancer burden, in the presences of competing health issues, and an overburdened and inefficient health and development systems, palliative care remains a relatively unknown and low priority health agenda item. This is further confirmed by a dearth of evidence-based or programmatic research in the area of palliative care.

For the successful implementation of palliative care into health care system, there needs to be an emphasis on education, training and research. In Pakistan, facilities established to provide specialized healthcare needs like oncology care are not accessible to the majority since they are situated in urban cities and are expensive private sector facilities. Treatment is therefore beyond the reach of the majority [12].

With high rates of cancer even within the younger population, in 2002, Pakistan initiated its National Cancer Control Plan with the primary purpose of cancer control. The plan included building a health system prioritizing pain relief and palliative care alongside prevention and control efforts [13]. However, despite more than a decade of initiating a plan and recognizing a need for it, the development of palliative care services is far from adequate and Pakistan still struggles with implementation of the three pillars of palliative care [14]. According to a recent mapping of palliative care development, Pakistan is classified as a country with isolated palliative care provision [5]. Pakistan's ratio of services to population is one of the highest (1:90 million), which is in sharp contrast to the ratio in developed countries like Austria (1:34,000) or Australia (1:67,000) or even other populous Asian countries like India (1:42 million), China (1:8 million), and Indonesia (1:22 million) [5].

Political instability, economic conditions of country, poor infrastructure and only 1.8% of GDP being allocated towards health expenditures can be attributed to this ratio of services [12]. Health care facilities in neighbouring developing countries like India, are mostly disease oriented [15]. Pakistan follows a similar pattern with current policies and planning being disease oriented [16]. Palliative care suggests focusing on patient centred care, i.e., the needs of patient and family [15]. The prime goal of palliative care is to alleviate suffering and improve of quality of life for patients with advanced illnesses. This is responsibility of a team, comprising doctors, nurses, counsellors, social workers, and volunteers and should start as soon as a chronic life threatening disease is diagnosed [15]. This model of interdisciplinary, multi-dimensional team is an area where work needs to be done in Pakistan. It would involve a paradigm shift in the way health delivery is perceived and received by the health community as well as the general population.

Barriers to Palliative care

At present in Pakistan, the major barriers to palliative care are an uncommitted government, lack of drugs and an unrecognized specialty. To establish and improve palliative care in Pakistan, two areas that need priority focus are the availability of opioids and education and training in palliative care. Without a palliative care module being incorporated in undergraduate and postgraduate curriculums of medical and nursing colleges, the specialty will not be recognized and services will not grow [12]. For an institution to obtain

morphine, they have to go through four different authorities, and the whole process is complicated and takes approximately six to eight months. So while morphine stock outs are not an issue currently, the process of obtaining it is very tedious and it can only be prescribed by a few authorized physicians. This process may work for patients living in an urban setting close to the healthcare facility but it is of little use to patients living in areas with limited or no healthcare facility. For these types of patients, the only recourse is returning to their homes without continued access to palliative care. To improve palliative care, the recommendation for emerging countries is to make the process of obtaining access to morphine simpler, available in more locations and with fewer restrictions [12].

Palliative Care in Nursing

Generally, palliative care nurses need to develop special holistic skillsets through experience as well as training in order to help in caring for patients needing palliative care and their families. It requires a mix of clinical skills as well as an ability to provide psycho-social, and culturally appropriate care for the patient as well as family. This would include taking into account religious as well as cultural beliefs and life experiences when communicating with the patient and care providers. The competency level required by palliative care nurses is holistic and includes a wide range of skills that require communication and interpersonal skills [17]. It requires compassion and focus in anticipating the needs of the patient and family.

In Pakistan, the image of the nursing profession in general is still that of a physician helper who is involved largely in following the instructions of the medical team. Nurses are not seen as actively engaged in the process of decision making and has little or no communication or coordination with health care team. A distinct hierarchy between the medical team and nursing team exists in which the medical team dictates and the nursing team implements without any input. Breaking this mind-set requires not only empowerment of nurses with knowledge and practice as well as the confidence to be part of the decision making process, but also requires that the medical team recognizes the role of the nursing team as partners in care. The empowerment process of Pakistani nurses to become active palliative care nurses begins with education and knowledge enhancement. At the medical school level, teaching future doctors that palliative care involves partnering with nursing staff and a holistic approach. Whereas at the nursing school level, curriculums need to support and endorse palliation with on-going training for patient specific need identification like fatigue, nutrition requirement and pain management. Currently, the Pakistan Nursing Council, the licensure body of nursing in Pakistan, does not offer any certification or diploma in palliative care nursing [12].

Apart from the academic curriculum, the mind-set of the general population will also require to be changed. In the majority of the cases, public perception amongst Pakistanis is that medical doctors are more knowledgeable and nursing staff's role is not to engage or give advice but just to follow doctors orders. Since palliative care requires a high level of communication skills with the patient's family as well, nurses are not trained or never expected to address a patient and family's need for spiritual or psychological care. These domains are still expected to be addressed by the medical team. The division of work is unclear and nurses are not equipped or trained with the skills needed to generate discussions with individual beliefs, spiritualities and cultures [18]. Therefore it is imperative during training that nurses should be exposed with different types of case studies, different religions, rituals

revolving around death and dying through role plays, clinical simulations, and other strategies to enhance their professional practice [19]. Palliative care education should also emphasize the principles of effective communication so nurses are able to carry out patient assessment and development of management plans.

Generally policy makers are responsible to develop and review curriculum in any country [18]. In Pakistan, the nursing curriculum is the responsibility of the Higher Education Commission [20] and Pakistan Nursing Council [20]. As per the author's knowledge, they have not discussed any idea to develop comprehensive curriculum for palliative nursing [20].

Review of Existing Pakistani Nursing Curriculum

A review of the Pakistan Nursing Council website indicated that there are 112 Diploma nursing programs, 24 Post Registered Nursing programs, 22 generic BScN programs, 2 programs offering a general Master of Science and one institution offering 2 year part time modular program on Oncology/Cancer nursing [21].

The published curriculum revealed that the Diploma curriculum had a total of two hours which was dedicated to care of the dying patient and care of the body after death [20]. The introductory psychology course had four hours dedicated to effects of culture on illness. In year two of adult health nursing course, there are 15 hours dedicated to cancers and under the topic of management there is just a reference to palliative therapy. Similarly, the Pharmacology course had one module dedicated to chemotherapy.

The Generic BScN curriculum [21] showed that there was one unit in the fundamentals of nursing course which had one unit of two hours in which the concepts of loss and grieving as well as death and dying are covered. In the pathophysiology and adult health nursing course, there is a unit in which cellular adaptation and aberrant cell growth is covered. While the former covers the entire cell adaptation and aberrant cell growth, the latter focuses on the nursing care of cancer patients and treatment modalities. There is no mention of the word "palliative care". In Paediatrics which is offered in the third year of the program there is two hours devoted to care of a child receiving Chemotherapy. Both the diploma and generic BScN curriculum have no clinical hours and no specification for the number of hours in palliative care or cancer setting.

In 2011, one private teaching university introduced an elective course titled "Concepts of Palliative Nursing" to meet the gaps in the national nursing curriculum. By combining academia and nursing services, the course was developed for generic BScN students and staff working in Oncology and Home Health Care Services. These isolated efforts need to be built upon and incorporated into the national nursing curriculum, if we expect to make any consequential change in palliative care in Pakistan.

Recommendations

Considering the present scope of palliative care there is an immense need of training, teaching and structured services in Pakistan. Palliative care nursing is also in need of development since very few institutions have nurses specialized in palliative care on their oncology team. Most of the nurses are trained on the job by physicians and some may have attended short courses or workshops.

The present nursing faculty need to incorporate palliative nursing as a stand-alone module into the existing oncology courses. Clinical

exposure to palliative patients' needs to be the cross cutting theme across the curriculum both in inpatient and community settings. The introduction of palliative care into the curricula of the under graduate education of all doctors and nurses is recommended as an efficient way to broaden the base of palliative care coverage at the national level [15].

To effectively integrate palliative care into developing countries there must be appropriate national policies that deal with medicine availability (particularly opioids); education of health care workers and the general public. There needs to be implementation of palliative care services at all levels of society along including the National Health Plan for funding of palliative care service delivery [2]. Palliative care education programs need to identify national opinion leaders responsible for education, e.g., deans of medical and nursing, schools who are willing to work and change existing educational curricula and courses and develop new ones.

The other important aspect is to identify target audiences, those who will require education to increase their awareness and change their attitudes, knowledge, and skills related to palliative care. Like in other developing countries, it is important in Pakistan to actively engage the media and heighten public awareness of the need and benefits of palliative care. Since most patients with life-limiting illnesses prefer to be at home and they will primarily receive their care from family members and friends; it is also important that they are equipped with the skills and knowledge necessary [18]. In a resource restricted environment, the role of the palliative care nurse will extend to this group as well and they have the ability to play a key role because of their more frequent interaction with the patient and family members.

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