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Review Article

Palliative Care in Pakistan: Current Landscape, Challenges, Progress and the Way Forward

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ABSTRACT

Due to a rising global trend in ageing, non-communicable diseases and serious health related sufferings, a dire need for palliative care is emerging. Palliative care not only focuses on relieving suffering and improving management of complex health problems of the patient, it addresses it in the context of family dynamics and social settings making it a quint essential need globally. The greatest need of palliative care as reported in the literature is in the lower-middle-income countries (LMIC) where 78% of the global palliative care needs are. This review article will focus on the development of palliative care in Pakistan, a LMIC.

Introduction

The substantial improvement in life expectancy globally is not only resulting in a rapid rise in ageing population but additionally bringing about unique challenges in health care due to a concomitant increase in burden of various diseases. According to the global estimates, the number of older individuals will double by 2050 and is further projected to reach a staggering figure of 2.1 billion (21%) from the earlier 1 billion figure (8%) reported in mid twentieth century. A major consequence of this demographic shift has been the rise in development of chronic and self-limiting illnesses. Looking at the mortality figures globally, 70 percent of global deaths in 2015 were as a result of non-communicable diseases (NCD) of which 75 percent occurred in low resource countries. Similarly, cancer burden is significantly rising as well. According to World Health Organization (WHO) estimates from 2019, cancer has become the leading cause of death in 112 of 183 countries [1]. Unfortunately, most of this global increase in the next 50 years will be coming from low resource country as well (400% in low-income countries, 168% in middle-income countries and 53% in high income countries) [2].

The associated rise in morbidities and mortalities related to chronic and life limiting illnesses and complex health care needs has led to emergence and significance of palliative care. Palliative care aims to improve the quality of life of individuals and families with life threatening and self-limiting illnesses through prevention and holistic management of physical, psychosocial and spiritual suffering using a team based approach. WHO now recognizes it as a basic human right to health, yet only 14% of the patients who need palliative care actually receive it, and that too mostly in European countries [3]. According to a global estimate, an alarming 20 million individuals are in need of palliative care with 78 percent of those concentrated in LMIC where there is already limited availability of palliative care services [4]. The wide disparities and health inequalities between high-income and low-income countries, as mentioned above, may increase the burden and cost of people and societies significantly, requiring a re-focus on the development and implementation of palliative care in low-resource settings. The World Health Assembly recognized and endorsed this dire need for countries to develop national strategies for the provision of palliative care by making it a part of universal health coverage which is now gradually gaining ground [5].

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Healthcare in Pakistan

Pakistan is a developing multiethnic country, the second largest in South East Asia and the fifth most populous country in the world with a population of over 220 million [6]. Since its inception it has been striving to achieve political stability with sustainable social development. The health care delivery system of the country established in 1970s consists of both public and private sector; public sector being jointly administered by the federal and provincial governments with the districts largely being responsible for implementation. The public health care system consists of a three tiered structure beginning with basic and rural health units and dispensaries (primary care) in tier 1, the district health quarter hospitals (secondary care) in tier 2 and the tertiary care hospitals in tier 3. Because of the poor infrastructure of the primary health care, people are unwilling to avail it. In 2010, the management of public health hospitals and government facilities were delegated to the provinces to allow greater autonomy but still faces major challenges hampering its progression as expected.

Thus, it is the private sector that is at present serving 70 percent of the population [7]. Private sector is far from being organized, being unregulated and expensive, with distinct entities varying from a modern well-equipped hospital to a local general store with a medicine counter providing unregulated healthcare. They follow varied economic models ranging from non for profit organizations to business models healthcare set ups. It is estimated that 39% of the population suffers from multidimensional poverty yet almost 90% of healthcare expenditure is out of the patient's pocket mostly from private sector [8, 9].

With increasing economic pressures, insufficient financial and human resources, inadequate public health care and unregulated private health care, absence of insurance coverage, the health care system continues to deteriorate with declining health related socio-economic indicators. Although the country has tried to make improvements in its healthcare delivery system like participating in millennium development goal program, introduction of public private partnerships and restructuring national health policies, the focus remains on expansion and strengthening of treatment facilities with less attention on prevention and palliation. Pakistan's total expenditure on health in 2018 was reported to be 3.2% of it's GDP in 2018 as per the World Bank which in itself shows the government's inability to regard health as a priority. The country is currently facing a double burden of disease with NCD accounting for more than 50% of adult mortality with a projection of around 3.9 million deaths by 2025 as a result of NCD alone [10]. Cancer has also emerged as a major health issue which is reflected by the estimates for new cancer cases in the country standing at a staggering figure of 170,000 to 200,000 yearly with many presenting at an advanced stage requiring palliation from the beginning [11].

Although the oncological services have expanded in the country, the focus remains more on curative aspects of cancer rather than the palliative aspects. The American College of Oncology recommends that every advanced cancer patient should be seen by palliative care team within 8 weeks of receiving a cancer diagnosis but presently the country lacks the financial and human resources to accomplish such guidelines [12]. These statistics indicate a dire need for restructuring and reforming the current health care system that is inclusive of palliative care delivery [13]. With insufficient and poorly regulated health care facilities, low budgetary allocations for health, lack of support or prioritization on health sector by the government and resource allocation mismatch, inclusion of palliative care services in health care system seems a remote possibility at present. For successful implementation of palliative care into any health care system, an emphasis is needed in three key areas namely education, training and research all of which are lacking in the country as far as palliative medicine is concerned.

Current Scenario of Palliative Care Provision in Pakistan

Palliative care in Pakistan as a discipline is still in its infancy stage and remains a low priority health agenda. A survey conducted by the international observatory at the end-of-life care (IOELC) on palliative care facilities reported Pakistan as having the least favorable ratio of patients served by a palliative care facility, with only one service identified for a population of around 160 million [14]. The worldwide hospice palliative care alliance (WHPCA) similarly published a dismal statistic for the country, reporting that less than 1% of the Pakistani population had access to palliative care services and categorized Pakistan as level 3a (isolated provision of palliative care) [15]. Despite of identification and recognition of palliative care as a priority and a cost-effective strategy for management of cancer in its action plan for control of chronic diseases earlier on, the development of palliative care services is far from adequate and is not yet recognized as a component of healthcare [16]. Pain relief which is an integral part of palliative care specially in cancer patients remains a hugely neglected area in the country.

Only 2% of the terminally ill patients having access to opioids for pain management with only 300 patients having received pain relief for palliation out of the 350,000 needing it according to the 2012 figures reported by WHPCA [9, 17]. The annual consumption of morphine (mg/capita) by a country gives an indirect index of access to palliative care. Pakistan falls in the lowest quartile of opioid analgesic consumption (1-10 mg morphine equivalent per 1000 inhabitants per day) as per the data from a longitudinal study on 66 countries [18]. Even though the country ranks at eight in of the list of top 10 producers of opium and morphine globally yet when it comes to availability of palliative pain relief, it is rated as one of the worst countries. In addition to the regulatory authorities restriction on opioids, inadequate law enforcement system is leading to an illicit production, consumption and trafficking of opioids, contributing to the unavailability of these agents in the healthcare settings where it is most needed. Short acting narcotics are not available in the country with supply of morphine, labelled as a controlled drug, being inconsistent and variable. Approval of different ministries and governmental departments for procurement coupled with strict regulations of opioid procurement and dispensing, forces patients in the community to seek end of life care in a select few tertiary care and military hospitals with limited quota allocated to them.

Formal palliative care services presently are provided by only a handful of institutes in the country and that too primarily in the private sector with a few hospices in Karachi, Hyderabad and Rawalpindi run mainly by faith based or other charitable based or non-governmental based organizations. As a specialty multidisciplinary service, palliative care currently is being offered at five major tertiary care hospitals in Pakistan;

two of them based in Karachi that includes the Aga Khan University Hospital (AKUH) and the Indus Hospital (TIH) along with Islamabad based Shifa International Hospital (SIH) and Shaukat Khanum Memorial Cancer Hospital and Research Center (SKMCHRC) at Lahore and Peshawar [19]. Some isolated provision of palliative care services is also being offered at some other centers like Liaquat National Hospital, Karachi.

Out of the above mentioned institutes, AKUH and SKMCHRC have dedicated palliative care units with both in-patient and out-patient based services provided by a multidisciplinary team. AKUH additionally offers home based palliative care services as well providing comprehensive palliative care visits and end of life care. A study on the impact of the outpatient palliative care consultations in terminal patients at AKUH concluded that the palliative care visits significantly improved the symptom burden in patients with a terminal diagnosis thus validating the need for further development of such care facilities across Pakistan [20]. An institute of palliative care is also in the pipeline in Cancer Care hospital and Research Center in Lahore which will be the first in the country.

Challenges to Palliative Care Provision: Facilitators and Barriers

A number of barriers and facilitators exist for palliative care provision in Pakistan which will be discussed under four headings based on the four-component approach of the WHO public health model for effective palliative care integration reiterating its stance on using public health strategy to integrate palliative care into the community [21].

I Personal Level Facilitators and Barriers

Paucity and dearth of awareness of palliative care in the public as well as health care professionals is a huge barrier in the development of this discipline in this region. Lack of trained personnel, fear regarding the knowledge and use of opioids and non-inclusion of palliative care in the nursing or medical curriculum in the public sector is contributing to the delay in the growth of palliative care in Pakistan. Although there has been increasing efforts to address this awareness in health care providers through some growing research in this area in Pakistan which is a positive aspect. Majority of the responders (92.5%) from a survey on awareness of palliative care among health care providers in Pakistan expressed the need for inclusion of palliative care in the curriculum at all health care levels [22]. Most had good understanding regarding palliative care although they were dissatisfied with the palliative care being currently provided attributing it to lack of training [22]. Additionally, in another local survey on Pakistani doctors, physicians have expressed eagerness to get trained in this discipline [23]. A positive step based on this need assessment has been the acceptance of palliative medicine as a specialty for postgraduate degree with the introduction of pain and palliative care fellowships nationally for physicians interested in providing palliative care.

Further institutions, particularly in public sector, must take this forward to build upon this positive trend. Other than lack of skills, some other barriers in development of palliative care has been the restrictive cultural and religious views regarding end of life care (EOLC) which is an important component of palliative care delivery. Although the western trend seems to have a more medicalized approach to end of life and death, denying death as a natural process. Islamic societies and eastern culture on other hand are more accepting of death which can be of huge advantage to physicians in EOLC. Yet, despite this, death is a rarely discussed topic and in fact considered a taboo subject. With a predominant family autonomy overriding individual autonomy in Pakistani set up, the huge pressure of "not to tell" and hiding diagnosis and prognosis from the patient to protect them from harm results in excessive burden on both the families as well as the health care providers leading to either over treatment or futile treatment being administered in EOLC.

The extended family is often consulted in decision making with the cultural values of the relatives affecting the delivery of medical care in important areas like resuscitation measures, medications, medical interventions, artificial feeding and withholding of nutrition and fluids, thus impacting the end of life discussions and dying process. With no formal legislation or policies or protocols in place, EOLC and advanced care planning thus hugely remains an undiscussed topic. Breaking bad news is another task and skill in palliative care, where a lack of formal structured training has been identified at both undergraduate and postgraduate level in research conducted on postgraduate residents at a teaching hospital in Pakistan [24]. Breaking bad news was identified as a lacking skill by 40% of the physicians in a local survey and expressed desire to have formal training in it [23]. Although the Pakistan Medical and Dental Council has included communication skills in undergraduate curriculum, the emphasis on formal teaching of this essential skill is far from adequate in most of the medical institutions in Pakistan.

II Policy Level Facilitators and Barriers

Lack of support and collaboration from the government along with paucity of funds and resources and prohibitive and restrictive opioid regulations have repeatedly been identified as major challenges and barriers in the delivery and growth of palliative care in this region. Identification of palliative care as a priority in its national action plan for prevention and control of chronic diseases has been a huge development in positive direction although the need is now of the implementation of a formal palliative care development plan. Pakistan can take the example of regional countries like India who have managed to include palliative care in it's state policy and thus expanding the delivery of palliative care utilizing effective collaborative efforts between governmental and non-governmental sectors. In addition, a formal plan and strategy to regulate and monitor the access and distribution of opioids is urgently needed and which can happen through urgent attention and action from the key stakeholders in the country.

III Health System Level Facilitators and Barriers

Shortages and paucity of trained health professionals and lack of contextual palliative care models in palliative care is another major setback and barrier to growth of palliative care in the country. Further training programs catering to all health care professionals, both medical and allied, need to be introduced at all health care facilities and institutions in order to progress further. The training should be structured to involve all districts and regions and the trained personnel could then

be sent to each district and utilized for further training of additional staff in those districts. The leading models of palliative care that is hospital based and home-based care provision needs to be implemented through establishment, expansion and strengthening of treatment facilities dedicated to palliative care in the country. Currently dedicated home-based palliative care service is only being offered by Aga Khan University. The model of care needs to be replicated by other institutes across the country and further cost-effective strategies and innovations like use of telephonic consultations and other technologies can be made use of to further expand palliative care delivery.

IV Organizational Level Facilitators and Barriers

Lack of facilities, infrastructure, resources, poor management and understaffing in health care have all been contributing to the delay in progression of palliative care delivery in the country. Learning from the lessons in neighboring countries, empowering families of patients and utilization and training of community volunteers to provide palliative care is the way forward.

Conclusion and Way Forward

Although the seeds of palliative care have been laid down in the country, Pakistan still has a long way to go as far as successful integration of palliative care into the health care system is concerned. For successful implementation and progress of palliative care delivery in the current Pakistani health care system, the emphasis needs to be in 3 key areas of education, training and research. Going forward requires a number of strategies as recommended below:

i. Incorporating palliative care into the existing health care infrastructure using the already tried community-based models featuring home based and integrated services in neighboring countries using a public health approach.
ii. Making effective use of innovative technologies and strategies in palliative care delivery like tele health and video conferencing thus reaching out to the deprived individuals with poor access to palliative care facility.
iii. Patients, families and key stakeholders must be actively involved in palliative care communication and advocacy. Involvement of national associations, faith based and philanthropic organizations, governmental and non-governmental sectors for development and implementation of a national policy in palliative care should be a first step in the propagation of palliative medicine in the country.
iv. Establishing hospices and dedicated palliative care units in all institutions of the country which could also act as training grounds in palliative medicine for various health care professionals.
v. Academic development of palliative care should be another key area which can be initiated with introduction of palliative care in nursing and medical curriculum throughout the country followed by development and offering of basic courses, certificates and diplomas in palliative care.
vi. Drawing from successes, experiences and lessons learnt from regional countries, mobilization of community workers and volunteers can be a key step. Establishing and running a volunteer care program from general public to assist in the delivery of palliative care programs in the country can be a way forward having been utilized effectively in various countries.
vii. Funding through local and national charities for successful implantation of palliative care programs.
viii. Introducing a wide range of capacity building initiatives like building a core group of trained palliative care physicians who are able to develop palliative care team in various regions in the country who not only serve their respective regions but also then take up the task of training and educating other health care professionals in palliative medicine.

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