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Palliative care in Pakistan

ROBYNA IRSHAD KHAN

“Surely we belong to Allah and to Him shall we return”

(Holy Quran - 2:156)

Abstract

Pakistan is a developing country of South East Asia, with all the incumbent difficulties currently being faced by the region. Insufficient public healthcare facilities, poorly regulated private health sector, low budgetary allocation for health, improper priority setting while allocating limited resources, have resulted essentially in an absence of palliative care from the healthcare scene. Almost 90% of healthcare expenditure is out of the patient's pocket with more than 45% of population living below the poverty line. All these factors have a collective potential to translate into an end-of-life care disaster as a large percentage of population is suffering from chronic debilitating/ terminal diseases. So far, such a disaster has not materialised, the reason being a family based culture emphasising the care of the sick and old at home, supported by religious teachings. This culture is not limited to Pakistan but subsists in the entire sub-continent, where looking after the sick/elderly at home is considered to be the duty of the younger generation. With effects of globalisation, more and more older people are living alone and an increasing need for palliative care is being realised. However, there does not seem to be any plan on the part of the public or private sectors to initiate palliative care services. This paper seeks to trace the social and cultural perspectives in Pakistan with regards to accessing palliative care in the context of healthcare facilities available.

Pakistan is a predominantly Islamic country situated in a geographically sought-after location, surrounded by India, China, Iran and Afghanistan. The Indian subcontinent was divided in 1947 on the basis of religion. However, India and Pakistan still share a strong cultural bond. Death and the events preceding it, like all other significant events in human life, are seen through the lens of religion and culture. This article attempts to describe the practices in Pakistan as far as accessing palliative care is concerned, keeping this dual lens in mind. However, to illustrate the context, one has to view the matter with an eye on the existing healthcare structure, which is characterised by inequalities in access to healthcare in general; and assigning of low priority to palliative care in particular. This results in a marked disequilibrium between the need for, and availability of, palliative care in the country.

Health is not a priority

The public healthcare structure in Pakistan was established in the 1970s and consists of three tiers, with facilities for referral to the next level. The first tier consists of basic health units (BHUs), rural health centres (RHCs) and dispensaries. BHUs are outpatient facilities that employ a doctor and paramedical staff. Dispensaries perform the same function, but have only paramedical staff, while RHCs provide outpatient and some basic inpatient care. Currently, there are 5395 BHUs, 4813 dispensaries and 572 RHCs providing primary healthcare in the country (1). The second tier consists of *tehsil* headquarter hospitals (THQs) and district headquarter hospitals (DHQs). There are 280 THQs and 108 DHQs in the country. The third tier consists of 39 tertiary care hospitals that are located in major cities.

Pakistan, the sixth most populated country in the world (2), is ranked 186th out of 189 countries in the matter of total expenditure on health as a percentage of the gross domestic product (GDP) (3). More than 45% of the health budget is directed towards curable diseases at the tertiary care level. In

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a population exceeding 191 million, less than 5% are above the age of 65 years. In spite of the fact that Pakistan has a relatively young population, WHO statistics (4) reveal that systemic diseases, such as stroke, ischaemic heart disease, chronic obstructive pulmonary disease, tuberculosis and diabetes mellitus, are five of the ten leading causes of death, while about 40% of the total burden of disease is due to infectious and communicable diseases, including Hepatitis B and C (5). The public healthcare system is unable to cater to the needs of the very poor (46.5% of the population, according to the United Nations Human Development Report, 2014), so a major section of the population is forced to access private healthcare, which has a dominant presence, particularly in the urban areas. According to the WHO global health expenditure database, in 2013, 86.8% of Pakistanis' total expenditure on healthcare was out-of-pocket expenditure. This is about 2% less than in 2010 (6).

Private healthcare is not an organised system, but an assemblage of many entities, varying from a well-equipped tertiary care hospital to a local general store with a medicine counter, providing care (7). These entities follow different economic models, ranging from philanthropic hospitals, where anyone can receive care and which do not have cost considerations, to for-profit institutions running purely on business models. There is no identified regulatory authority for private healthcare providers. The Pakistan Medical and Dental Council (PMDC) is responsible for regulating hospitals attached to all medical colleges/universities. However, its own functioning has been severely hampered by corrupt practices which resulted in its dissolution in 2015 and the promulgation of a presidential ordinance to run its affairs (8).

Against the backdrop of an inadequate public healthcare system, an unregulated and expensive private sector, the absence of health insurance coverage, employer benefits and old-age benefits, and the absence of free cancer screening, the incidence of cancer is high, with most patients presenting at a late, incurable stage (9,10). The National Cancer Control Programme (NCCP) was established for prevention, early detection, treatment, palliation and pain management, according to WHO guidelines in 2002. The programme was initiated in accordance with a WHO directive and supported solely by the funds provided by WHO. It failed to make any impact as the Pakistani government did not provide the required financial support. From the list of the top 10 prevalent cancers, breast and cervical cancers were selected for screening in the DHQs of a certain area. Palliative care has not been given any consideration in the NCCP (11,12).

No formal palliative care services

Formal palliative care services are almost non-existent in the country. Public healthcare and philanthropic private care have failed to prioritise palliative care as an important target, while for-profit hospitals regard it as a non-profit entity. The National Health Policy, 2009, formulated by the Ministry of Health, Government of Pakistan, identified strategies to bring about an improvement in the delivery of healthcare and the overall

health status of the population of Pakistan. Palliative care planning was not one of them (13).

In the private sector, basic palliative care is available in Shaukat Khanum Memorial Cancer Hospital, Lahore, Aga Khan University Hospital (AKUH), Karachi, Children's Cancer Hospital, Karachi (14) and a few Christian hospices in Karachi, Hyderabad and Rawalpindi. None of these facilities has separate palliative care units. The AKUH has an established home health service that arranges physicians, nurses, physiotherapists and phlebotomists to visit patients' homes and provide the care required. Formal home-based services are not available elsewhere. However, general practitioners are agreeable to visit a patient at home and provide care. The lack of formal home-based services necessitates repeated trips to hospital by patients in need of palliative care and results in death in hospitals. This dilemma is more pronounced in the rural areas, where patients have to travel long distances to hospitals in the urban areas to access care.

The International Observatory at the End of Life Care (IOELC), while publishing a survey of palliative care facilities around the world, has observed a "least favourable ratio" of patients served by a palliative care facility in Pakistan, as only one service was identified for a population of 157,935,000 (15).

Sickness and death – the Pakistani perspective

Pakistan is a predominantly Muslim country, 97% of the population follows Islam (16). Islam encompasses the life of its followers in its entirety. Muslims look to the holy Quran for guidance in their daily lives and try to emulate the Sunnah, the teachings, deeds and sayings of Prophet Muhammad [peace be upon him (PBUH)]. In addition, they follow the "hadith", collections of reports claiming to quote verbatim the words of Prophet Mohammad on any matter, and "ijtihad", a process of legal reasoning and hermeneutics through which the jurist-mujtahid derives or rationalises law on the basis of the Quran and the Sunnah on the basis of the knowledge of the precedent ("ilm") (17).

Illness is usually accepted as "God's will". Similarly, Muslims believe that the time of death is pre-ordained. In the Quran, verse 68 of chapter 40 of Ghafir says:

"It is He who gives life and causes death. And when He decides upon a thing He says to it only: "Be!" – and it is."

Despite accepting a preordained time of death, Islam encourages its followers to access healthcare and seek treatment and relief from pain and suffering. There are many hadith to this effect. Abu Hurayrah narrates that Prophet Muhammad (PBUH) said:

"There is no disease that Allah has created, except that He also has created its remedy." (Sahih-al-Bukhari 7.582).

Sickness is considered a test of patience by Allah and Muslims are expected to show forbearance and persist in their faith. Muslims believe that though sometimes the reason for an illness or disease may not be apparent, God knows best and

does what is in the best interest of humankind. Suffering is considered a part of being alive and forbearance of hardship is greatly rewarded in Islam (18). Pain and suffering are considered to be a trial from God and in return, God expiates the sins of the sufferer and cleanses him/her for eternal life (19). Sickness is expected to make human beings remember their mortality, modify their ways and do good deeds. Islam asks its followers to remember death every day and reflect on their existence in the context of its temporariness.

Death is viewed as a transition from the temporary world to an eternal life. Similar to other monotheistic religions, belief in "life after death" is one of the pillars of the Muslim faith. In Urdu, the national language, the word used for death is "*inteqaal*", which literally means "transfer". Death is the transfer of individuals from this temporary world to an eternal abode, where their deeds and misdeeds during their earthly sojourn are judged. Recitation of the holy Quran and *Kalimas* near a terminally ill patient is a common practice, and stems from the belief that listening to the Quran provides emotional and mental peace to the dying, and relieves the pain and unpleasant sensations associated with transition.

Pakistan is a patriarchal, hierarchical society. "Family" rather than an individual is the basic unit of society. When an individual suffers from a disease, the entire family gets involved. The family makes decisions for its members, and duties and responsibilities are divided. Males are considered the head of the family and are seen as the breadwinners, while females are responsible primarily for raising the children and looking after the household. These norms are changing with time, with more and more females participating in the economic upkeep of the family. The elders of the family are considered wise and given respect due to their age (20). Any illness is a "family affair" in Pakistan.

Despite a clear acceptance of death in the religion, culturally it is a taboo subject. Discussing death or dying is considered a bad omen and is generally avoided. Negative thoughts are believed to lead to negative outcomes, so the emphasis is on optimism even in the face of the inevitable. The majority of patients are reluctant to hear bad news and refuse to participate in discussions when a terminal disease is suspected. Usually, bad news is given to a close family member(s) first (21). The family members discuss the matter among themselves and decide whether to inform the patient about the diagnosis and prognosis or to hide the truth (22). Physicians and nurses usually accept this concept of "family autonomy" and develop a practical approach to ethical dimensions. In practice, the choices of close family members are respected and healthcare providers do not insist on revealing the diagnosis directly to the patient. The law requires competent adult patients to provide consent for medical interventions. However, in the absence of medical litigation, consent for surgical or palliative procedures is often signed by the next of kin rather than a competent patient him/herself, as a truly informed consent cannot be obtained without explaining the diagnosis and prognosis. There has been no incident of a patient suing his/

her physician for taking consent from a family member for his/her procedure.

Protecting patients from bad news is considered an act of love and compassion in Pakistani and Indian families. Therefore, despite the religious emphasis on telling the truth, the fact that a patient has a poor prognosis is hidden from him/her. The skill of how to break bad news is formally taught in only a few universities in the two countries. Consequently, most physicians are untrained in this skill and are reluctant to break bad news (23,24). The lack of candid discussions about imminent death creates a "culture of silence" during end-of-life care. Many dying non-cancer patients are brought to hospital for curative treatments. Overtreatment at the end of life is commonly observed. Recent surveys (25,26) have shown patients' preference for knowing the truth and being informed about their prognosis and life expectancy. This might be an indication of a changing trend.

Patients and families in the know about the diagnosis and prognosis prefer that the patient should receive care at home and die with his/her loved ones at his/her bedside. The commonly expressed wishes of the elderly are to "die while walking on one's own feet" and to die "surrounded by loved ones." Another reason to opt for death at home is the cost of healthcare. Patients and families want to avoid excessive and unnecessary expenses as healthcare facilities are oriented only towards providing a cure. The author has been teaching bioethics to nursing students for many years and routinely asks the same question every year: "Given a choice, how would you like to die?" The majority of these nurses work in intensive care and high dependency units. Not one of them would want to die in the hospital. A "good death" is conceptualised as one without pain and suffering, without a prolonged illness, in the presence of loved ones, at an age when one has taken care of one's worldly responsibilities, and at home. Dying in hospitals is generally considered undesirable. People from other Muslim cultures have a similar preference for dying at home (27).

Care of the old and sick

The Quran gives clear directions on the way Muslims must treat their parents. Chapter 17 of *Al-Isra*; *Juz*' 15; Verse 23 says:

"... Allah has ordered you to worship none except Him, and to be good to your parents. If either or both of them attain old age with you, do not say 'fie on you', nor rebuke them, but speak to them with words of respect."

Similarly, in the context of the type of behaviour and character that should be acceptable to Muslims, verse 151 of chapter 6 of *Al-An'aam* says:

"Say, 'Come, I will rehearse what Allah hath (really) prohibited you from: join not anything as equal with Him; be good to your parents; kill not your children on a plea of want. We provide sustenance for you and for them; come not nigh to shameful deeds. Whether open or secret, take not life, which Allah hath made sacred, except by way of justice and law: thus doth He command you, that ye may learn wisdom."

In Pakistani society, parents are considered part of the family and often, head of the family for as long as they are alive. The concept of grown up children moving out of their parents' home does not exist. Extended families reside together and it is common to find three generations living under the same roof. Children grow up with the belief that taking care of their parents and grandparents is their duty. Daughters leave their parents' home after marriage, but sons are expected to stay with their parents and take care of them in their old age. Internal and external migration for economic motives is leading to a gradual shift towards smaller family units, especially in urban Pakistan. However, leaving old parents alone is still not a common practice. The Quranic teachings cited above, ie that respecting and taking care of one's parents is a Muslim's religious duty, gain in importance when one's parents or grandparents are ailing or old. Abandoning parents who are sick or old is considered a shameful act and society judges an individual who does this as a bad person. It is the prevalent belief that "your children will treat you the same way you treat your parents as they are learning from your role modeling". This practice holds true for people of the sub-continent practising other religions as well. Previous studies have demonstrated that Muslims and Hindus raised in the subcontinent believe that their families will look after them when they are sick, while those raised in Britain feel they should explore palliative care facilities before counting on their families at the end of life (28).

Besides parents and close family members, Muslims are expected to be kind and merciful to others when they are sick. A *hadith* narrated by Muslim [2699] describes Prophet Muhammad (PBUH) as saying:

"The one who stays with the one who is sick, and takes care of him and looks after him has done good by serving him and caring for him, and Allah, may He be glorified and exalted."

Verse 195 of Chapter 2, *Al-Baqarah* in the Quran says:

"And do good. Truly, Allah loves Al-Muhsinoon (the good-doers)."

Visiting a sick/injured person is considered the duty of a Muslim. Providing relief to the patient or his/her family in any way possible is a good deed. The purpose of the visits is to honour the patient, pray that his/her suffering ends, seek forgiveness for inadvertent or deliberate wrongdoings in the past, and to offer physical, financial or emotional support. These visits include meeting the patient's family. It is understood that the family of a dying patient is suffering with him/her, and deserves sympathy and relief.

Terrorism, lawlessness and poor security measures (29,30) have led to a considerable brain drain, with younger professionals from the urban parts of the country moving abroad and leaving behind their old parents, who are either living alone or with servants. Yet the concept of old age homes is completely alien in the country. This, however, will increase the demand for palliative care services.

Healthcare providers' perspective

Palliative care is neither taught in undergraduate medical and nursing curricula in Pakistan, nor in any postgraduate training programme, in a comprehensive manner (31). Sporadic courses and rotations are offered in oncology programmes (32). Aga Khan University has a short rotation in the family medicine programme, in which palliative care and some related skills are taught. In general, on the completion of their training, doctors and nurses are insufficiently equipped to deal with dying patients (33). The situation is not very different in India (34). Also, the skill of how to break bad news is not taught formally and healthcare providers usually learn it informally by observing their seniors. Given that patients expect doctors to have a positive outlook, doctors try to oblige by tiptoeing around the subject when the prognosis is poor. A silence prevails, with everyone discussing the short-term day-to-day management of the illness but being unwilling to discuss the ultimate. Words such as "cancer" and "death" are usually avoided and are alluded to indirectly by the use of other words such as "mass" and "no hope for life". Usually, the bad news is given to a close family member. It is an acceptable norm to discuss the treatment options with the family, and to even obtain consent for the treatment from the family rather than a competent patient. The concept of "family autonomy" is accepted by healthcare providers and practised without much difficulty. Decision-making usually starts at a very late stage and discussions pertaining to end-of-life care almost never take place. This is bound to be so in the absence of openness and in a situation in which all concerned refuse to utter the word "death". Some healthcare providers returning to the country after training abroad in centres where palliative care is taught find it difficult to adjust to this family-based decision-making. With time, there has been a change and some patients want to write advance directives. However, there is no legal provision supporting advance directives or living wills. In the absence of patients' own expressed wishes, family decision-making comes into play. Sometimes, conflicts arise during decision-making at the end of life. For example, the family may be divided on the choice of the decision-maker. Patients usually do not discuss or appoint a surrogate. Where they do, the selected surrogate maybe overruled by the person footing the bill, who then automatically assumes the role of decision-maker. This situation can be challenging for physicians and nurses who are new to the setup.

Often, a close family member walks into the clinic or hospital first to talk to the healthcare team with a request not to reveal the diagnosis and prognosis to the patient. There is an entrenched belief that hearing bad news will kill hope and the patient will give up (35). Patients feel closer to nurses as they spend a longer time with them. In cases where the healthcare team has been asked not to disclose the diagnosis/prognosis to the patient, nurses feel a huge moral pressure not to answer direct questions honestly and to hide the truth.

In the absence of palliative care services, families are usually advised to take the patient home, as there is "no hope". This

practice is acceptable to everyone as a major portion of the healthcare expenses is out-of-pocket expenditure. The unfortunate aspect of this practice is that dying patients have nowhere to go to receive symptom-control care. Admission to a healthcare facility usually means undergoing a battery of unnecessary laboratory tests before receiving the required palliation, which increases the cost of care unnecessarily. This situation can be a nightmare for patients without families, as home-based care is insufficient and costly.

Euthanasia

The sanctity of human life is highly valued in Islamic teachings. The concept of euthanasia or physician-assisted suicide is unacceptable in all Islamic schools of thought. It is forbidden to take a life, whether one's own or another's. Verse 32 of, chapter 5, *Al-Ma'idah* in the Quran says:

"...if anyone slew a person – unless it be for murder or for spreading mischief in the land – it would be as if he slew the whole people: and if anyone saved a life, it would be as if he saved the life of the whole people."

Human beings are not considered the owners of their bodies. The real owner is Allah; human beings are given the stewardship of the body. They are expected to look after the body, seek treatment for ailments and live a balanced life. It is not for them to decide when to end their life, but for God to take their life at the preordained time. Euthanasia is completely forbidden. However, there is no restriction on pain relief to alleviate suffering. Undue suffering has no place in Islam. Pain relief with strong analgesics such as morphine is allowed, even if it hastens death (36), if the intention is to alleviate pain and suffering, as actions are judged by the intentions behind them. The Prophet (PBUH) has been quoted as saying:

"Actions are dependent upon their intentions."
(*Sahih al-Bukhari- 1*)

Scholars have emphasised that the acceptance of the inherent value and significance of pain and suffering should not prevent Muslims from seeking pain relief (37, 38). However, in Pakistan, very few patients have access to strong opioids for pain relief at the end of life. Those who do might still opt not to use morphine as they fear that deep sedation will prevent them from reciting the *Kalima*, a declaration of faith in Islam that Muslims are expected to recite when death is imminent. The belief that pain and suffering wash the sins of a dying person and purify him/her for the eternal life helps mask the faults of a deficient healthcare set-up, in which patients have no choice but to bear the pain.

The prolongation of life by artificial means when medical futility is established is disapproved of. Futile care is also to be withdrawn in the case of brain death. Prophet Muhammad (PBUH) was quoted as saying:

"No one should wish for death because of a calamity befalling him; but if he has to wish for death, he should say:

'O Allah! Keep me alive as long as life is better for me, and let me die if death is better for me.'"

Narrated by Anas bin Malik (*Sahih al-Bukhari* 5671)

Well-equipped intensive care units are limited and in high demand in Pakistan. The cost of care is very high in these units. Patients/families readily agree to the withdrawal or withholding of futile treatment as very few can afford the treatment in the first place. Due to cost constraints, many patients and families want the care to be withdrawn even before they realise that the treatment is futile, creating ethical dilemmas for the treating physicians.

Pain relief for palliative care

"A palliative care programme cannot exist unless it is based on a rational drug policy, including ready access of suffering patients to opioids." (World Health Organization, 2002) (39). Pakistan is eighth in the list of the top ten countries producing opium and morphine (40). Unfortunately, it is also among the worst rated countries when it comes to the availability of pain relief services for palliative care. The World Palliative Care Alliance records that in 2012, more than 350,000 people needed pain relief for palliation in Pakistan, but only around 300 people received any (41). Morphine is a "controlled drug" in the country. A limited quota is allocated to tertiary care and military hospitals. This quota is insufficient to provide for acute pain management of the patients in these hospitals. Palliative pain management is not given priority while allocating this small resource (42). Chronic pain management services are available in limited centres. Oral morphine is available in these centres and is dispensed by the prescription of credentialed pain consultants. Control measures instituted to prevent the illegal use of the drug entirely disregard the necessity of analgesia for those suffering from severe pain at the end of life. Ironically, *charas* (a form of cannabis) and heroin (diamorphine) are freely available, another of the many paradoxes existing in the country (43). Physicians sometimes advise patients to procure *charas* for relief of severe cancer pain. A book chapter reviewing the state of palliative care services in Muslim countries describes Pakistan as a country where the availability of morphine for palliative care is virtually non-existent (44), resulting in miserable deaths for patients dying of cancer or other painful diseases.

Conclusion

Palliative care medicine involves the adoption of a holistic approach to the treatment of physical pain and symptoms, the management of psychosocial issues and addressing the spiritual needs of those suffering from incurable diseases. In Pakistan, the family-based culture and a strong religious belief system may be providing psychosocial and spiritual support, but non-existent palliative care services, the absence of pain/symptom management facilities, dearth of trained healthcare personnel, minimal resource allocation to healthcare by the government, lack of prioritisation of palliative care in the health indicators and unrealistic narcotic policies leave a

good amount of the responsibility of providing a peaceful “*inteqaal*” on Allah.

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