

Special Edition  
"Palliative Care and Oncology:  
Time for Increased Collaboration  
and Integration"

## Commentary

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# Difficulties in Developing Hospice or End-of-Life Care Hospitals in Developing Countries

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According to the United Nations (UN) statistics, Pakistan is currently listed as a developing country. Implementing palliative services has come across as a big challenge and possesses various risks, not only because it is a developing country but also due to communal extremism. Muslims being the predominant community, the country has been dealing with extremism in the name of Islam. The citizens are constantly under the threat of extremists and religious leaders who enforce them to follow stringent rules and restrictions, defying which can lead to dangerous consequences.

Pakistan being an Islamic Republic, females are the most affected amongst all when it comes to seeking medical or palliative services. The strict rules and regulations restricts female patients from seeking palliative support, since they are expected to be handled by female staff nurses only. This comes across as rather inconvenient when treatment is sought for terminally ill patients as well as for sexual, gynecological dysfunctions.

Another major concern being that majority of the palliative service providers and institutes are biased, entertaining only patients belonging to their own community. It has often been observed that Muslim patients have better access to these services and are treated well when compared to those belonging to the other religions, presumably because they are considered unrewarding.

Reportedly, 40% of the country's population lives below the poverty line, where access to basic necessities such as clean food, water and sanitation is a luxury; things that only the privileged can afford. Apart from this, famine, starvation and susceptibility to infections and deadly diseases have been major causes for massive mortality. For families of patients with such advanced or end stage diseases, it is often a huge liability and hence they are at times just left to die unattended, or fall prey to mercy-killing by some quacks, where they are quite inhumanly gotten rid off.

Expatriated below are some of the cultural challenges in Pakistan, which need urgent attention:

### Gender-Based Challenges

As elucidated above, lack of female staffs, nurses and healthcare providers for treating female patients and *vice versa* is a constant challenge for implementing gender unbiased palliative services, in an Islamic Republic like Pakistan.

### Lack of Proper Palliative or Hospice Care Centers

The lack of enough palliative or hospices care centers in Pakistan shows just another loophole in the country's system and incomprehensiveness of the authorities, which is the biggest of all concerns.

It is not only the officials in charge of the medical care of the country, but also the negligent and injudicious attitude of medical professionals/clinicians which adds to the poor

state and under-developed facilities. Underprivileged families of patients who are declared terminally ill by the doctors, although reluctantly, often prefer to discontinue further treatment and medication, discharging them from medical facilities and care. This is either due to lack finances and help from the government or at times to decrease the liability this brings on the family and the healthy feeding stomachs. However, the better educated and financially sound sect of the society who can afford the required treatment and life support machinery, tend to arrange for healthcare professionals and treatments at home, if not for visiting doctors. Such patients often find themselves isolated in their own homes for the rest of their lives, in the hands of home nursing staff, physiotherapists and doctors. Certain hospitals refuse to treat the elderly patients in their advanced stage of illness due to the huge turnover of younger patients, especially the ones in Lahore like Shaukat Khanum Cancer Hospital.

#### Unregulated Old Age Homes

There are very few old homes in Pakistan to documents and most of the times they are actually the places where the terminally ill elderly are left by choice or by their TOO BUSY near ones till they breath their last.

#### Low Socio-Economic Status

Low employment rate in developing countries like Pakistan, comes across as a serious add on to the present socio-economic situation, forcing people to indulge in crime and other inhumanely activities. Deadly diseases, inaccessibility to clean water, food and sanitation, as well as famine, starvation and reportedly, 40% of the country's population lives below the poverty line, where access to basic necessities such as clean food, water and sanitation is a luxury; things that only the privileged can afford. Apart from this, famine, starvation and susceptibility to infections and deadly diseases further explain the reason for the stagnant, if not deteriorating socio-economic status.

#### Social Stigma

In our society, certain diseases are looked down upon, for example, sexually transmitted diseases (STDs) and acquired immuno deficiency syndrome (AIDS). Lack of diagnostics and the required infrastructure for research on such diseases are poorly developed due lack of funding from the Scientific Research Council. Moreover, if at all diagnosed, people are too shy to disclose their disease until death.

#### Lack of Awareness at the End of Patient

In cases where the patients themselves are uneducated or under informed about the disease condition, available treatments and facilities or any available help for the poor, the situation worsens. In general, there is a lack of awareness amongst the people on emergency measures, precautions and about their right to free or subsidized medical care, if any.

#### Lack of Awareness amongst Attendants or Caretakers

In many cases, patients, when diagnosed with end stage diseases, are completely unaware or uninformed by the doctors about the gravity of the situation. For example, when it comes to treating end stage cancer, many are still subjected to chemo and radiotherapy with little chances of survival. Research has shown that many a time's doctors are involved in making money without counseling the patients how bad the stage of the disease is, with little or no benefit of chemo or radiotherapy. Here, some doctors have more focus on commercial point of view, than the actual benefit of the patients. They linger on to the situation until the patient reaches end stage.

Sometimes, interventions like chemotherapy and radiotherapy at the wrong stage play havoc with the patient's life, decreasing their span of survival and increasing their agony.

#### ICU Setup

End-of-life management requires a specialized setup, especially ICUs for managing critical care patients, even though most end stage patients are DNR (Do Not Resuscitate). However, patients other than cancer patients deserve all the life support including ventilators, cardiac shock, life support medicine like adrenaline, atropine, etc. Hence, hospice should have well-organized ICU setups as well.

#### DONOR Recipient

In cases of liver and kidney transplants, patients who are given immune-suppressing drugs needs critical care, whereas, transplant rejection patients again need hospice because as there is little chance of survival otherwise.

#### Financial

Most of the times, hospice care, although available, is not affordable to the financially lower class, reasons of which are well explained above.

#### Registration

Since the government of Pakistan does not permit registration of any hospice units without proper grant permissions, there are very few centers with the required facilities for treatment.

#### CONCLUSION

Timely implementation of the above mentioned suggestions will help in the overall improvement of the conditions in the country. The responsibility of creating social awareness regarding the medical conditions, technological and global progress should be taken over by the government. Moreover, it is the employment of well trained caretakers, and efficient staff in well facilitated hospitals without the interference of religion or extremists that will help the people grow.