



United Nations Open Ended Working Group Substantive Input Focus Area One: Access to Health Care Services

Access to Geriatric and Palliative Care Services

By 2030, low and middle income countries will hold approximately 70% of cancer deaths worldwide. However, only two percent of Indians that need palliative care are able to access these specialized medical services. Approximately ten million Indians are estimated to need palliative care services. However, access to specialized medical care, including palliative care services, is limited in India. However, the need for palliative care is made pronounced by patients with late stages of disease at presentation.

The need for palliative care in India is great also because of lack of access to curative options, a rising geriatric population, and increasing rates of cancer. Kerala, a state in southern India, continues to be the leader in palliative care services. In 2008, the government of Kerala recognized the need to integrate palliative care services in to the state's standard health care model. At that time, Kerala held over eighty palliative care facilities, while the rest of the Indian states held less than sixty. The 2019 revision of this policy recognizes palliative care as a human right to be recognized across the continuum of care from community to tertiary level, in both the public and private sectors.

Barriers to Access

Health care services, including general and specialized care such as geriatric and palliative care services, tend to be concentrated in urban areas at tertiary medical facilities.

However, the majority of older persons in India live in rural areas. Other barriers to access for Indian elders include lack of transportation to these centralized medical centers, lack of geriatric and palliative training for Indian medical professionals, decreased mobility, loss of income and financial constraints, lack of family support in gaining access, as well as dependency on family members in the setting of decreased social engagement.

The number of palliative care facilities available is significantly unbalanced between Kerala and the rest of the country. Many states in India have no palliative care facilities of any type.

Opioid Access

The World Health Organization has listed morphine as an essential medicine. However, access to morphine, even for palliative patients, remains extremely limited or completely unavailable in low and middle income countries. Although opium is grown in India, access to opioids differs greatly from state to state. The states of Uttar Pradesh, Madhya Pradesh, and Rajasthan grow opium; this opium is exported to create opioid drugs worldwide. Very little opium, produced in India, is saved for use within the country.

In 1985, India passed the Narcotic Drugs and Psychotropic Substances (NDPS) Act; this Act intended to control the possession, diversion, sale, import and trade of psychotropic substances, including opioids. The NDPS act did not differentiate between opioids used for medical purposes, including the use by palliative care patients, from recreational use. Many cite this act as a draconian piece of legislation: included is a mandatory death penalty for repeat violations involving large quantities of drugs.

The NDPS has been critical in the lack of access to opioids for medical purposes within India. Healthcare facilities or pharmacies that wish to provide opioids must have four to five different licenses from different branches of the Indian government; these More than half of regional cancer centers in India do not carry morphine or have physicians trained in opioid therapy. From the passage of NDPS to 1998, morphine use in India fell by 92% while global use increased by 437%. In four states, including the state of Tamil Nadu neighboring Kerala, opioids can be prescribed for “emergency” use only.

Access to palliative care is considered critical to health, and thus, for those with pain as a result of life altering illness, continued advocacy for opioid access in India is critical.

References:

- Azeez, EP Abdul, and G. Anbuselvi. "Is the Kerala model of community-based palliative care operations sustainable? Evidence from the field." *Indian Journal of Palliative Care* 27.1 (2021): 18.
- Bandewar, Sunita VS. "Access to controlled medicines for palliative care in India: gains and challenges." *Indian J Med Ethics* 12.2 (2015): 77-82.
- Harding, Richard, Shoba Nair, and Maria Ekstrand. "Multilevel model of stigma and barriers to cancer palliative care in India: a qualitative study." *BMJ open* 9.3 (2019): e024248.
- Lijimol AS, Krishnan A, Rajagopal MR, Gopal BK, Booth CM. Improving Access and Quality of Palliative Care in Kerala: A Cross-sectional Study of Providers in Routine Practice. *Indian J Palliat Care*. 2020 Oct-Dec;26(4):500-505. doi: 10.4103/IJPC.IJPC_17_20. Epub 2020 Nov 19. PMID: 33623312; PMCID: PMC7888431.
- Saini S, Bhatnagar S. Cancer Pain Management in Developing Countries. *Indian J Palliat Care*. 2016 Oct-Dec;22(4):373-377. doi: 10.4103/0973-1075.191742. PMID: 27803557; PMCID: PMC5072227.



United Nations Open Ended Working Group Substantive Input Focus Area Two: Social Inclusion

Widowhood as it Impacts Access to Housing, Infrastructure, and Inclusion in Decision-Making Processes

India is home to nearly 55 million widows comprising roughly 10% of the country's female population, as compared to 3.3% globally. During the COVID-19 pandemic, hundreds of thousands of women were recently widowed, many of whom struggled to get financial support from the government.

Widows in India are a vulnerable population caught up in a rapidly changing society. India presents a unique dichotomy: while women in general have gained more education and independence, this gain has not translated into an improvement in the condition of widows. These women remain marginalized and vulnerable in society, facing stigma, grief, isolation and loneliness.

The grief of a woman losing her husband is complicated in the Indian setting by the loss of her standing in society and community. The sudden loss of autonomy and access to money and property even more marginalize the widow. In the event the widow has a daughter who is not married, the widow has the responsibility of securing a husband and dowry for the daughter. Interpersonal conflicts between the widow, her children, and their families also impact the widow's enforced dependence on her children.

Widowhood brings with it immense psychological consequences as well; for example, as a non-widowed mother is an essential part of a wedding, but a widowed mother may be forbidden to participate in the ceremonies.

While no statistics have been compiled on legal recourses available to widows in India, anecdotal evidence suggests that even if such an option exists, most widows do not take advantage of it. It is culturally acceptable as an older woman to live in an ashram or beg for a living, rather than to put her child through public shaming that legal action would bring. Often, public stigmatization leads to self-stigmatization in widows leading to a decrease in self-esteem.

Some groups of widows face even more discrimination. Widows of men that were drug users and died of HIV who may suffer from HIV themselves are labeled as "injecting

drug use” (IDU) widows. They are at increased risk of mental health issues due to poverty, stigmatization, discrimination, in addition to the mental health effects of HIV.

As an example, the city of Vrindavan sees many widows that have been abandoned by their families and that come to the banks of the Ganges to spend the last days of their lives. The exact number of widows in Vrindavan is unknown but estimates suggest that as many as 6,000. Some sources have documented the difficulties these women have in obtaining and accessing bank accounts, Aadhar cards, etc. Undocumented and unstudied are trauma of abandonment, and the devastating set of circumstances that force these women to live on the streets in old age. Political strife also creates “half widows” in Kashmir and in other areas; these women do not know if their husband is alive or dead. Women married as infants find themselves widowed at a very young age. Again, these groups receive very little official attention.

With the exclusion of widows from society, it is not difficult to imagine that they are not an active part of decision-making process in the country. So much so that there is not even enough research and evidence on the topic. The infrastructure of the Indian legal system as it stands now, does not support widows, their physical and mental well-being.

We need reform in Indian society that enables women and girls to achieve self-actualization. We need to end social stigma associated with widowhood. We need to broaden opportunities for economic empowerment. We need laws that bring elder abuse to the forefront, penalize family members that abuse and abandon elderly women, and empowers those that have lost their husbands. Overall, we need comprehensive national aging policies that promote spaces and avenues for healthy aging. Only this way can we begin to tackle the mental health and wellbeing crisis facing widowed women across the country.

Literature cited:

1. Chandrasekhar CP GJ. Widowhood in India. Available at: https://www.networkideas.org/wp-content/uploads/2017/10/Widowhood_India.pdf. Accessed February 17.
2. Invisible Women, Invisible Problems. Available at: <https://www.un.org/en/observances/widows-day>. Accessed February 17.
3. M M. Rising debt, no widow pension: COVID-19 crisis brings Maharashtra’s vulnerable women farmers to the brink. Available at: <https://www.firstpost.com/india/rising-debt-no-widow-pension-covid-19-crisis-brings-maharashtras-vulnerable-women-farmers-to-the-brink-9566751.html>. Accessed February 17.
4. Mohindra KS, Haddad S, Narayana D. Debt, shame, and survival: becoming and living as widows in rural Kerala, India BMC Int Health Hum Rights. 2012 Nov 6;12:28.
5. Study on widows at Vrindavan. National Commission for Women, 2009-2010.