Measurement of cancer stigma in India: challenges and opportunities

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Inequality in health care is pervasive in low- and middle-income countries (LMICs). Various studies show that cancer and associated stigma is a sharp wedge that deepens and widens these existing disparities.[1,2] Stigma with a diagnosis of cancer is a major issue in certain societies in LMICs where cancer is often perceived as a life-threatening event, evoking feelings of uncertainty, fear, and loss in individuals, irrespective of their prognosis.[3,4] These emotional responses contribute to the stigma surrounding the disease. Specifically for women, it also uncovers the underlying lack of agency embedded in patriarchal societies where they have fewer basic rights to education and health, choice of partner, determining a family, mobility, and labor participation. The fear of being stigmatized leads some to repeatedly experience episodes of anxiety and depression, which, in turn, may prompt them to keep their cancer diagnosis a secret from their family members and friends. This hinders their ability to access cancer care and seek help, thus, delaying diagnosis along with poor uptake of cancer care services.[5] These collective experiences emphasize the importance of addressing stigma and improving community support systems to encourage cancer early diagnosis and prevention.

In India, the cancer incidence was estimated to be 100.4/100,000 in 2022.[6] Given the increasing incidence, cancer stigma acts as a barrier to both care and support.[7] While there have been limited attempts to measure cancer stigma using a standardized scale in India, this need has been brought out through small exploratory studies.[7] The first comprehensive cancer stigma scale (CASS)[8] developed and validated in 2014 has been applied for lung cancer in the United Kingdom[9] and the United States.[10] As a 25-item scale, it assesses six different aspects of stigma; awkwardness, avoidance, perceived severity, policy opposition, personal responsibility, and financial discrimination. Using a standardized validated scale facilitates cross-geographical, demographic, and cancer subtype comparisons, enabling precise and targeted public programs. The Shame and Stigma scale for measuring head and neck cancer stigma has been validated in China, Greece, Brazil, Canada, and Malaysia[11] with only one study attempting to validate this in India.[12]

India has a unique cultural context which comprises myriad belief systems about health and illness. There is limited formal research on the correlation between cancer stigma and delays in seeking help. The crucial first step to studying cancer as a stigmatized condition would be to create a robust validated tool to measure stigma – one that can capture local beliefs (for example, sins of a past life), is customizable for cancer type (for example, shame associated with oral cancer-related disfigurement) and regional differences (for example, in levels of fatalism, and for stage of patient journey). This would allow for priority setting analyses to compare stigma levels between cancer types and geographies (especially for rural populations where stigma is high) and identify the highest need. Furthermore, researchers conducting pilot studies on social campaigns to reduce stigma would be able to evaluate their effectiveness in a robust manner. Once our understanding of cancer stigma matures through site or cohort studies and there is a body of evidence for prevalence of stigma as well as effectiveness of interventions, the tool could be periodically deployed through the cancer registry programme to be able to understand stigma trends. Taken together, these would aid policy makers to refine and target strategic public health investments at the national level.

Contributors

IK, AP, and LS conceptualized the manuscript. IK wrote the first draft of the manuscript. All authors contributed to finalizing the manuscript.

Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this article.

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