



# Unmet Needs of Oral Cancer Survivors in India: A Perspective

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## Abstract

Oral cancer is one of the predominant forms of cancer that alters the livelihood of survivors. They can have many unmet needs. However, very little research has been done on this topic, especially in India. This commentary piece discusses what unmet needs could mean, how the disease culminates differently and creates different realities, how the research and policymaking have been done and how it could be improved.

## Keywords

- ▶ oral cancer
- ▶ unmet needs
- ▶ psycho-oncology

Oral cancer is a chronic disease with risks of fatality, and it requires patients to undergo operations many times leaving the patients with limited functionality. Because of the nature of the disease, the difficult treatment regime, and the treatment outcomes, patients face “psychological morbidity” because of the functional deficits. In the first year of treatment post-diagnosis, emotional functioning is at its lowest.<sup>1</sup> To cope with the changes, patients adapt many coping mechanisms. Those mechanisms are denial, projecting themselves as someone else, repression or variations like suppression or regression.<sup>2–4</sup>

This combined psychological and physiological deficit leaves patients with increased needs for their day-to-day functioning. These could be emotional needs, financial needs, information needs, etc. Whether the needs are met depends on the intersectionality of the needs and the factors that affect those certain needs. It is estimated that around 90% of newly diagnosed cancer patients experience unmet needs.<sup>5</sup> Although unmet needs as a concept have been a part of the larger international psycho-oncology sphere, there has not been a working definition for unmet needs. For deliberating further research and understanding the associated concepts, a working definition of unmet needs is necessary for cancer research. Here we can define unmet needs as those needs that a person has not been able to satisfy yet. The needs shall correspond to all the aspects that may arise from the disease that the person has or had.

This is even more necessary in India as oral cancer puts a lot of burden on the healthcare delivery systems as it is the most common form of cancer for men in India.<sup>6</sup> India accounts for one-third of the global burden for oral cancer.<sup>7</sup> Adding to that, very little is known regarding the unique needs that oral cancer survivors might have. With treatment regimes including processes like chemotherapy, surgical resection of the buccal cavity, and/or radiation therapy, patients and survivors often experience toxicity because of the treatment and are often distressed about changed appearance and functioning that includes difficulty eating, drinking, and speaking.<sup>5</sup>

More importantly, in India, the nature of oral cancer is different as cancers caused by smokeless tobacco override smokable tobacco. Cancers of gingival and buccal mucosa are common because of the habit of placing the tobacco quid in the oral cavity, while in the west, cancer of the tongue or floor mouth is more common.<sup>8</sup> To understand such a nuanced phenomenon, culturally sensitive tools need to be used in India. For carrying out surveys, there exists validated questionnaires like Health-Related Quality of Life (HRQoL), European Organization for Research and Treatment of Cancer (EORTC), Cancer Needs Questionnaire – Short Form (CNQ-SF), and Cancer Survivors Unmet Needs (CaSUN).<sup>9–12</sup> Of these, CaSUN is the most culturally fluid questionnaire. This questionnaire having 42 questions is divided into four broad sections named “information and medical care issues,”

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“quality of life,” “emotional and relationship issues,” and “impact cancer of cancer on your life perspective.” Through the questions, the major needs of the sample can be quantified. The confusion associated with the use of questionnaires like HRQoL is the absolutist approach in the adaptation of these in contexts where they may not fit well; this may skew the data. For identifying context-specific problems, culturally appropriate tools need to be developed.

Existing literature shows that most needs fall under the psychological domain. Thus, future studies could be performed focusing specifically on emotional needs or similar cross-sectional studies could be performed to refine the data. However, the gap in literature so far is the lack of an understanding of what each of these unmet needs is. In the case of “emotional needs,” there is no clear definition of emotional needs demarcating what constitutes emotional needs. If further research on this area is to be based on the existing literature, what constitutes emotional needs is open for vast interpretation and needs to be defined. The CaSUN, how much culturally sensitive it may be, does not contain emotional needs specifically and does not define the four major categories of needs that the questionnaire constitutes. This asks for the development of more appropriate tools for research on unmet needs and a greater magnitude of research on the same. Another peculiar set of needs which might persist for any chronic disease is communication needs. In a study performed in Taiwan, health information needs were at the top.<sup>13</sup> In the Hyderabad-based study as well, the following emotional needs were interpersonal communication needs and medical information needs.<sup>8</sup> Information sharing is mostly based on communication regarding the disease and the care regime. For interpersonal communication needs, tailored counseling is needed based on the subjective experience of the patients. Regarding information communication needs, the DOTS program is a landmark example of using messaging technology efficiently to manage the disease. Instant messages acted as reminders for patients to get their medicines and provide information regularly. Instant messaging technology made patients adhere to the treatment regimen. Many patients used their mobile phones to call healthcare providers regarding doubts, symptoms, treatment, and diet.<sup>14</sup> Information needs and communication needs should not be confused with each other. The absence of information will fall under the domain of information needs, while the information being provided in an unfamiliar language or the information provided with the use of jargon would fall under the domain of communication needs.

Especially in the last 7 years, there has been a lack of literature on unmet needs. Even the oral cancer management guidelines prepared by the Indian Council of Medical Research (ICMR) rely heavily on outdated literature and also foreign literature that might not be suitable for the Indian scenario.<sup>14</sup> This top-down approach of implementing Western research and healthcare models in developing countries is quite apparent across the global south owing to the global north having hegemony in public health research and global health outreach programs. This can be backed up by accounts

of Julie Livingston in her book “Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic,”<sup>15</sup> and China Mills in her book, “Decolonizing Global Mental Health: The Psychiatrization of the Majority World.”<sup>16</sup>

Additionally, India has put in place practical frameworks for the prevention and treatment of cancer, but the research has been preliminarily oriented toward prevention. In that regard, this lack of research on the post-treatment phase is a preclusion for the state machine to make policies accordingly. The need for state-led research and intervention is heightened as under the “minimum government and maximum governance” idea, the state has moved shifted itself from Fabian socialism to extreme liberalism by reducing government spending. Along with this, increased privatization leaves the healthcare industry at the behest of private players.<sup>17</sup> Insurance policies like Ayushman Bharat Yojana only act as a monetary intervention after the disease is acquired. Beyond that, the management of the disease is up to the care providers. Since no qualitative research has been done on this topic, there is great scope for qualitative research to add valuable information about the needs that oral cancer survivors have in India. Especially in India, qualitative and mixed methods would better capture the cultural and social nuances and add context to the problem to better devise policies. This is because most validated questionnaires used are appropriated for the Western context that would skew the data. But by using a qualitative approach like Interpretative Phenomenological Analysis (IPA), lived experiences of patients with the disease can be tapped into. Or else, if the surveys could be followed by interviews, contextual understanding of factors constituting the surveys can be probed. This will help us better evaluate the problems as the understanding of the disease varies from culture to culture. The same applies to meaning factors like “quality of life” or “best healthcare facility.” These things might mean differently to different cultures, communities, and individuals.

Given the fact that tobacco is being consumed in different forms and is a part of the sociocultural milieu in India,<sup>18</sup> culturally appropriate solutions have to be devised. Research on the unmet needs of survivors must be done to specify the needs of oral cancer survivors in India, specific to the context. A more culturally sensitive questionnaire must be validated for more refined empirical research in this area. Most importantly, research on oral cancer survivors would provide solutions that will be completing the whole cancer care regime. Other than spending on more research and putting new systems in place, existing resources need to be utilized without putting an additional burden on these resources. In India where communication needs are the second most unmet need according to a study by Varma et al,<sup>8</sup> using automated messaging services to deliver regular information to cancer patients and survivors could be one efficient solution. Tacit knowledge of doctors, nurses, and caregivers and their experience of treating oral cancer patients and dealing with their needs can be recorded to add to the existing knowledge to refine the quality of care. Moving further, along with policy reviews and research on unmet

needs of oral cancer survivors, existing resources of knowledge and tools of care need to be tapped into.

#### Conflict of Interest

None declared.

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