

LETTER to the EDITOR

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Research Gap in Health Literacy: Are We Overlooking a Possible Solution to Inadequate Cancer Screening in India?

Abstract

India has one of the highest oral cancer burdens and accounts for one out of every five cervical cancer incidences worldwide. Majority of these preventable cancers are diagnosed in advanced stages with poor prognosis and survival. World Health Organization supports health literacy as a measure for accomplishing sustainable development goals. Community trials have reported that health literacy-focused interventions improve cancer screening participation and adherence. In India health literacy research is unutilized for cancer screening. Majority of the research utilized proxy information using disease-specific knowledge, attitude, and socio-demographic characteristics for screening participation. Through this correspondence, we discuss the poor cancer screening coverage in India and the research gap in health literacy in Indian context. Without an understanding of the distribution of the components of health literacy and the development of context-specific interventions for improvement, it will be difficult for any technology or innovation to penetrate the community and increase screening coverage.

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Dear Editor

India accounts for one of every five incident cervical cancers (Aswathy et al., 2012) and one-third of oral cancers worldwide (Global Cancer Observatory, 2020). Majority of these preventable malignancies are diagnosed at an advanced stage, with poor survival (World Health Organization, 2014). Despite over four decades of the national programme in India for the prevention and control of common cancers, the breast, cervical, and oral cavity screening coverage among women (15–49 years) is just 0.6%, 1.2%, and 0.7%, respectively. Men's oral cavity screening coverage is 0.2% (National Family Health Survey, 2019-2021) (International Institute for Population Sciences, 2022).

Health literacy (HL) determines cancer screening adherence. The operational definition of HL is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (Ratzan and Parker, 2000). Developed countries have prioritized HL in their policies, practices, and research. The World Health Organization supports HL as a measure for accomplishing key Sustainable Development Goals (Liu et al., 2020). Cancer literacy is described as “all the knowledge a layperson needs to possess to understand the information and advice the health system has to offer regarding preventing, diagnosing, and treating cancer” (Diviani and Schulz, 2011). Better HL increases the likelihood of cancer screening uptake (Baccolini et al., 2022).

A community-based randomized trial utilizing health-literacy focused interventions among Black women living with human immunodeficiency virus reported significantly higher Pap testing rates compared to the

women in the control group. (50% vs. 21.9%, $p=0.025$) (Han et al., 2023) Another health literacy-focused intervention cluster randomized trial among Korean American women reported higher odds of undergoing a mammogram (18.5 times; 95% confidence interval [CI] = 9.2, 37.4) and Papanicolaou test (13.3 times; 95% CI = 7.9, 22.3) in the intervention group compared to the control group, thus successfully promoting cancer-screening behavior. (Han et al., 2017)

There is a dearth of HL research on cancer screening in India, which often uses proxy variables like disease knowledge and attitude, as well as socio-demographic correlates like education, socioeconomic status, and rurality (Changkun et al., 2022). Systematic reviews of these variables show significant regional differences (Pal et al., 2021; Thulaseedharan et al., 2019). Having good disease knowledge, positive attitude and favorable socio-demographic characteristics may not always translate into screening uptake.

Three-quarters of the study population in Kerala, the state with highest literacy, knew that Pap smear can detect cervical cancer early, yet only 6.9% had ever taken one (Aswathy et al., 2012). Higher education is not necessarily correlated with greater health literacy. Tamil Nadu with one of the best community-based screening programmes and health education systems, reported only 7%, 3.8%, and 0.9% of women undergoing cervical, breast and oral cavity examination respectively (International Institute for Population Sciences, 2022). Qualitative research from India revealed that even those who had heard of or experienced or opted for screening were uninformed of its purpose.

The rural, hard-to-reach and tribal communities are severely impacted. A study on tribal females from

Maharashtra reported that the majority of the women have not heard of cervical (80%) and breast cancer (64%) (Jha et al., 2020). Primary care physicians are the first point of contact for these marginalized communities and act as a custodian for providing health-related information and referral for cancer care to these populations. A study from Rajasthan on 157 primary healthcare professionals practicing in rural settings reported that the majority of professionals (88%) perceived that the rural patients were unwilling or afraid to talk about cancer. Most of the doctors (65.6%) directly referred the suspected cancer patients to higher centres without carrying out the initial investigations (Yadav, 2020). Indian cancer care pathway studies show that patients often consult a cancer-treating clinician months after symptom appearance (Datta et al., 2022).

A systematic review defined HL as an “ability of an individual to obtain and translate knowledge and information in order to maintain and improve health in a way that is appropriate to the individual and the system context”. HL includes knowledge of disease, health care, and health systems, as well as the ability to interpret and use this information to sustain health through self-efficacy and collaboration with healthcare providers (Liu et al., 2020).

Very few Indian studies have utilized validated instruments like Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFHLA), 6-Item Cancer Health Literacy Test (CHLT-6), etc., to examine the role of HL in cancer context and limited to only cancer treatment (Gupta et al., 2020). Research from Nepal found that better cancer literacy scores were significantly associated with screening participation while rurality, ethnicity, and education were not significant determinants (Koirala et al., 2021). Qualitative Indian studies have examined cancer screening barriers; however, these instruments were not used to quantify cancer literacy gap and its impact on screening.

Without understanding the HL gap and developing context-specific interventions, it will be difficult for any technology or innovation to penetrate and improve the screening coverage in the community. Research from India found that a mobile health innovation was user-friendly for community health workers but did not boost cancer screening self-efficacy in the community (Bhatt et al., 2021).

We acknowledge that breast and cervical cancer screening involves logistics, trained staff, and motivation from women, and these factors may operate as bottlenecks for screening. However, oral visual examination which requires minimal logistics also has unsatisfactory coverage. Low HL may be contributing to poor screening rates in addition to programmatic, health infrastructure, and financial barriers.

We urge that improving cancer literacy in India could be one of the potential solutions to inadequate screening. Research on HL research should be incorporated into the understanding of lower screening rates and developing context-specific models for identifying populations with low HL. Interventions tailored for these at-risk populations, such as health education, behavioral modifications, and

other supportive strategies will build self-efficacy in the community for cancer screening.

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Conflict of interest

The authors declare no potential conflict of interest.

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