

MINI-REVIEW

Using Implementation Science to Advance Cancer Prevention in India

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Abstract

Oral, cervical and breast cancers, which are either preventable and/or amenable to early detection and treatment, are the leading causes of cancer-related morbidity and mortality in India. In this paper, we describe implementation science research priorities to catalyze the prevention and control of these cancers in India. Research priorities were organized using a framework based on the implementation science literature and the World Health Organization's definition of health systems. They addressed both community-level as well as health systems-level issues. Community-level or "pull" priorities included the need to identify effective strategies to raise public awareness and understanding of cancer prevention, monitor knowledge levels, and address fear and stigma. Health systems-level or "push" and "infrastructure" priorities included dissemination of evidence-based practices, testing of point-of-care technologies for screening and diagnosis, identification of appropriate service delivery and financing models, and assessment of strategies to enhance the health workforce. Given the extent of available evidence, it is critical that cancer prevention and treatment efforts in India are accelerated. Implementation science research can generate critical insights and evidence to inform this acceleration.

Keywords: Cancer prevention - implementation science - oral cancer - breast cancer - cervical cancer - India

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Introduction

In 2012, approximately a million individuals were diagnosed with cancer in India, representing 7% of the global incidence (Ferlay et al., 2014). Oral, cervical and breast cancers - cancers that are either preventable and/or amenable to early detection and treatment - are the leading causes of cancer-related morbidity and mortality in the

country (Ferlay et al., 2014). Although India's National Cancer Control Programme was launched in 1976, large scale implementation of cancer prevention and control strategies has yet to take place, and public expenditures on cancer remain low (Pramesh et al., 2014). In this paper, we highlight implementation science research (IS) priorities that have the potential to catalyze cancer prevention in India.

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The three leading cancers in India are far more lethal than in high income countries, primarily due to delays in diagnosis and treatment (Mallath et al., 2014). Limited access to information, delays in health care seeking and diagnosis, and inequitable access to treatment are hypothesized as key contributory factors (Mallath et al., 2014).

This scenario has persisted despite the fact that research in India has been instrumental in identifying various low-cost approaches to cancer screening and detection. For example, randomized controlled trials have measured the impacts on mortality of visual inspection (VI) of the cervix followed by treatment of precancerous and cancerous lesions when implemented by different cadres of health workers with varying frequency (Sankaranarayanan et al., 2007; Sankaranarayanan et al., 2009; Shastri et al., 2014). In the case of oral cancer, a trial involving 191,872 individuals in Kerala, although underpowered to detect statistically significant reductions in mortality among all eligible individuals, found that screening was efficacious among those who adhered to three or four rounds of oral visual screening as well as among individuals using tobacco and/or alcohol, largely due to early detection and reductions in the incidence of advanced cancers (Sankaranarayanan et al., 2013). Breast cancer screening and early detection through clinical breast examinations are also being studied in India, with high rates of acceptance and adherence to diagnostic and treatment recommendations (Mittra et al., 2010; Sankaranarayanan et al., 2011).

Despite these promising findings, efforts to translate such evidence into public health policy and practice in India remain nascent and are yet to yield impacts in terms of improvements in cancer awareness, timely diagnosis, treatment access and survival (Chalkidou et al., 2014; Sullivan et al., 2014). Programmatic experiences in Tamil Nadu, the only state in the country to have scaled up services for the prevention of common cancers and other non-communicable diseases (NCDs), have revealed that effective translation of evidence hinges on a range of implementation issues, including context-specific communication strategies, provision of high quality services, linkages between screening, diagnosis and treatment, and uptake of evidence by policy-makers and health care providers (Krishnan et al., 2013). Indeed, a comprehensive “evidence-informed framework” is needed to guide the planning and implementation of cancer prevention efforts in India (Chalkidou et al., 2014).

IS, defined as the study of the uptake, implementation and sustained use of research findings in routine practice and program settings, can help bridge the evidence-practice gap - the gap between what is known based on the best available research and what is practiced routinely (Glasgow et al., 2012; Sivaram et al., 2014). Specifically, IS can help answer a range of questions related to how health systems can be strengthened to deliver cancer prevention and care services, such as how programs can reach at-risk populations and how services should be configured for efficient delivery and improved uptake.

In this article, we propose an IS framework for cancer prevention drawing on the IS and cancer

prevention literature and based on the World Health Organization (WHO)’s health systems framework. Using this framework, we describe IS priorities to promote screening, early detection and treatment of the top three cancers (oral, breast and cervix) in India.

Implementation Science Framework for Cancer Prevention

The use of IS to facilitate the uptake and sustained adoption of evidence-based health promotion strategies is gaining global recognition (Madon, 2008). In the United States (US), where cancer is the second most common cause of death, adoption of evidence-based interventions (EBIs) for cancer prevention and control has led to some reductions in morbidity and mortality (Sanchez et al., 2012). However, widespread use of EBIs remains a challenge even in higher income countries like the US due to a range of factors including the quantum of evidence available (e.g., the number of efficacy studies), availability, training and experience of service providers, congruence between research and field experience, availability of resources for service delivery, and community acceptance (Kerner et al., 2005; Sanchez et al., 2012).

A push-pull-infrastructure model has been proposed to understand and guide the process of translating EBIs in cancer control into practice (Kerner et al., 2005). According to this model, the uptake of EBIs is shaped by the generation and dissemination of scientific knowledge regarding interventions (“push”) in concert with efforts to increase the demand for interventions (“pull”) and investments in systems for intervention delivery (“infrastructure”). IS can help identify how push, pull and infrastructure-related factors intersect in the adoption of evidence-based approaches across the cancer control continuum. It can generate knowledge regarding cancer prevention and control strategies and identify effective ways to synthesize, communicate and disseminate this knowledge (“push” factors), discover mechanisms to improve service delivery through policies, medical innovations, and financing mechanisms (“infrastructure” factors), and promote an understanding of how social, cultural and economic factors influence the demand for and uptake of services across the care continuum (“pull” factors).

In this paper, we draw on the six building blocks of the health system as defined by the WHO - information, medical products and technologies, service delivery, health workforce, financing, and leadership and governance - to organize the push- and infrastructure-related IS priorities ((WHO), 2007) while pull-related priorities focus on community-level issues. In the following sections, we apply this framework to identify evidence gaps and needs that, if addressed, can accelerate oral, breast and cervical cancer prevention in India.

IS Priorities for Promoting Cancer Prevention

Community-level “pull” priorities

Lack of awareness and understanding of cancer is viewed as a key driver of poor outcomes in India. That

said, investments in cancer prevention education should be guided by an in-depth understanding of socio-cultural factors that pose barriers to the uptake of cancer prevention and control services such as cancer stigma and fear. Furthermore, rigorous evidence on ways to mitigate these barriers is needed.

On-going health education initiatives such as the anti-tobacco campaigns in India have yielded some valuable lessons. Tobacco education strategies have included pictorial warnings on cigarette packs, establishment of State tobacco control cells, engagement of television media (public and private), and use of billboards and short films. Prominent tobacco education messages and health warning have also been included in feature films in which the characters smoke or drink alcohol. One study among adult smokers in the state of Karnataka found that greater exposure to tobacco warning labels was associated with better knowledge regarding the health effects of smoking and lower nicotine dependence (Mallikarjun, 2014). Anecdotal reports suggest that these efforts have resulted in a substantial increase in knowledge about the adverse health impacts of smoking. Mumbai's success in reducing smoking in public spaces is illustrative. The implementation of the ban on smoking in public spaces was achieved through investments in the education of key stakeholders, including the public, municipal corporation, excise department, transport agencies, unions, police officers and restaurant owners, using print and television media. Educational activities were led by the Tata Memorial Hospital over a period of one year, and resulted in over a 90% reduction in violations of the ban (Gupta, personal communication). After two years of the campaign, which is now led by the Mumbai municipal corporation, compliance has been nearly universal.

Health systems-level "push" and "infrastructure" priorities

Health information: Research (including process, outcome and impact evaluations) can identify feasible, effective and affordable approaches to cancer screening and diagnosis. Such evidence should be not only communicated through the scientific literature but also disseminated among policy makers and program planners. Currently, there is no national-level repository of cancer prevention-related evidence or dissemination platform that is explicitly targeted at informing cancer prevention policy-making and program planning in India. The planned National Cancer Institute (Dhar, 2013) and the National Cancer Grid are well positioned to serve this role. Appropriate organizations and platforms at the state or regional level also need to be identified, and could include state cancer institutes or state health systems resource centers. These efforts may be complemented by leveraging the power of the internet.

Medical products and technologies: Products and technologies for prevention, screening, diagnosis and treatment are essential to an effective health systems response to cancer. Screening and diagnostic technologies such as rapid molecular assays can be game changers for cancer prevention, and research on such innovations should continue to be conducted in India.

In highly resource-limited settings, visual inspection-based approaches may remain the most feasible; even in these situations, performance may be improved by using technologies such as the Magnivisualizer, a low-cost magnifying device developed and tested in India (Parashari et al., 2014).

Information and communication technologies (ICT) can strengthen health systems responses to cancer by facilitating community outreach, health worker training, quality assurance, and service provision. For example, images captured by a simple digital camera have been used by the Nargis Dutt Memorial Cancer Hospital in Barshi, Maharashtra to train health workers to conduct visual inspection-based screening for cervical and oral cancers, facilitate program monitoring including health worker competency assessments, and educate communities (Sankaranarayanan, personal communication). In Zambia, mobile health applications and digital cervicography have been used in quality assurance, supporting a centralized web-based electronic records system with point-of-care data entry, telemedicine consultations, and patient education (Parham et al., 2010; Mwanahamuntu et al., 2011). Mobile phone-based communication can also help with patient follow-up and adherence to diagnostic and treatment recommendations. Such ICT applications need to be more widely implemented and tested in India.

Cancer screening, early detection, and treatment services: Identifying appropriate models for delivering cancer screening, early detection and treatment is an IS priority in India. It is unclear whether cancer screening efforts should focus on multiple cancers (as opposed to single diseases) and whether cancer screening should be offered along with screening for other NCDs such as diabetes and hypertension. Given the overlapping demographic and risk factors for the common cancers and other NCDs, such linkages may increase the efficiency of health outreach. Program experiences suggest that packaging screening efforts focused on multiple cancers or multiple NCDs is more cost-effective and increases community awareness and health care seeking overall; this appears to be the case even when there are variable levels of evidence in support of screening for these diseases. That said, these decisions are likely to vary across states in India because of differences in health system capacities, variations in the epidemiology of cancers and other NCDs, and the fact that health is a state responsibility. Careful documentation of the implementation of cancer screening programs under different epidemiological and health systems conditions across India can provide valuable information on the optimal method of cancer prevention program delivery in different contexts. Process and outcome evaluations of on-going national and state-level NCD prevention initiatives should be prioritized, and mechanisms and platforms for disseminating lessons learnt should be established.

Overall there has been little research focused on understanding the barriers to providing cancer prevention services in India. Experiences from around the country indicate that the organization of inputs such as funds, staff, equipment and drugs pose multiple challenges to effective and efficient service delivery. For example, staff

shortages and irrational distribution of specialists, lack of diagnostic equipment at the appropriate level of the health system, irregular transfer of funds and medication stock-outs can impact whether services are provided and the quality of care. Poor coordination of services across levels of the health system and public and private sectors is also likely to be important. In the case of the state of Tamil Nadu, political commitment, careful planning of service delivery and investments in human resources and health care infrastructure for visual screening for cervical cancer resulted in a little over 4.5 million women being screened over a two-year period, which accounted for almost a third of women in the eligible age group in the state (Tamil Nadu Health Systems Project, undated). Process evaluations of cancer prevention programs can provide important insights on how to improve service delivery.

Cancer prevention efforts should not only strengthen public service delivery, but also identify ways in which to link, partner and coordinate with the large and expanding private sector, while taking into account the strengths and weaknesses of each sector. For example, the public health system has far greater reach into rural areas than the private sector although the private sector may be better positioned to provide tertiary level care. Non-governmental organizations are a third source of cancer prevention services. They can increase the uptake of screening services through community engagement and promote accountability and quality of public and private care through independent monitoring and evaluation of programs. Although equitable and sustainable access to

cancer prevention and treatment services will require public sector leadership, success is likely to be contingent on effective multi-stakeholder partnerships.

Health workforce: An adequate and competent health workforce at all levels of health care is the foundation of a strong cancer prevention program. Screening efforts can achieve scale and be sustainable only if sufficient human resources are committed. Moreover, health care workers need to be trained, supported and supervised to ensure that they are delivering high quality services.

A variety of approaches can facilitate expansion in the health workforce. For example, in the case of oral cancer screening, there are nearly 100,000 dentists in India who could be mobilized for oral cancer screening (WHO, 2012; Oberoi et al., 2014). Engaging health care providers trained in alternative systems of medicine such as Ayurveda and/or task shifting to nurses as in the Indian state of Tamil Nadu are additional ways to increase the number of health workers available to promote cancer prevention. Research is needed to identify which approaches are feasible and effective under different circumstances. Recruiting nurses may be feasible in the southern states of Tamil Nadu, Kerala and Karnataka. However, nurses (and nursing schools) are in short supply in northern states such as Uttar Pradesh and Bihar. Alternative health care providers may need to be engaged in those settings.

Availability of an adequately trained health workforce for screening remains a concern. Issues such as the minimum training needed for acquisition of cancer screening knowledge and skills, implementation of high

Table 1. Implementation Science Research Recommendations: “Pull” Factors

1. Identify effective ways to increase awareness and understanding of cancer prevention and control across stakeholder groups.
2. Rigorously monitor and evaluate cancer education efforts, including through the inclusion of cancer knowledge questions in national surveys.
3. Examine the role of socio-cultural factors such as fear and stigma that pose barriers to the uptake of cancer prevention and control services.
4. Develop and test strategies to address barriers to access and utilization of cancer prevention and control resources.

Table 2. Implementation Science Research Recommendations: “Push” and “Infrastructure” Factors

<i>Health Information</i>
1. Generate and widely disseminate research and programmatic knowledge and knowledge products such as clinical guidelines and quality standards, pre-service and in-service training curricula, and reporting and monitoring tools.
<i>Medical Products and Technologies</i>
2. Identify and field test through demonstration projects, pilots, etc. innovations (e.g., HPV DNA testing using self-sampling) that can be used in point-of-care settings, improve performance of screening and diagnostic tests, and facilitate scale-up of programs.
3. Identify how best to leverage information and communication technologies to enhance community outreach, health worker training, quality assurance, and service provision.
<i>Cancer Screening, Early Detection and Treatment Services</i>
4. Identify appropriate service delivery models, including packaging of services for multiple cancers and NCDs.
5. Implement pilot and demonstration projects and monitor and evaluate on-going programs to identify barriers and facilitators to effective service delivery.
6. Explore role of and partnerships between public and private (non-profit and for-profit) institutions in service delivery.
<i>Health Workforce</i>
7. Examine alternative strategies to increasing the health workforce for cancer prevention and control such as through task-shifting.
8. Identify optimal ways to train, supervise and support health care workers.
<i>Health Financing</i>
9. Estimate economic impacts of cancer.
10. Identify cost-effective approaches for cancer prevention and care, ensuring financial protection, and financing service delivery.

quality training at scale, methods for monitoring of quality of care, and incentives to health care workers to provide high quality services (including alignment with existing incentives) merit attention from IS researchers.

Financing cancer prevention and control: Cancer prevention efforts should ensure access to affordable treatment. Out of pocket expenditures on NCD treatment have increased substantially in recent decades and is especially devastating in the case of cancer; one study of about 200,000 households found that the odds of catastrophic hospitalization expenditures were 170% greater for cancer than for communicable diseases (Engelgau et al., 2012). Insurance schemes that increase financial protection for the poor have been introduced at the national and state levels. In the state of Tamil Nadu, for example, low-income women diagnosed with cervical cancer receive cashless tertiary care at empanelled government and private hospitals through the Chief Minister's Comprehensive Health Insurance Scheme. However, anecdotal evidence suggests that increasing access to tertiary care in settings that do not adequately emphasize prevention and early detection reduces the cost effectiveness of financial protection mechanisms: patients get diagnosed at advanced stages when treatments are more expensive and less effective. More research is needed on the financial implications of cancer, the cost-effectiveness of various cancer screening approaches and service delivery models (such as packaging services for cancer with other NCDs), and the financing of cancer prevention and control services (including the use of incentives and other mechanisms to enhance service delivery).

Leadership and governance: India's national cancer control program dates back to 1976, illustrating the national recognition of and commitment to the issue. The launch of the NPCDCS in 2010 with the aim of integrating NCD prevention efforts within the framework of the National Rural Health Mission has provided further impetus. However, discussions with state-level cancer prevention program implementers revealed the importance of local leadership and good governance to realize the population health benefits of such national initiatives. A study of public and private facilities in the Delhi-National Capital Region found that the absence of a policy on cancer prevention, lack of leadership, and limited funding were reasons underlying the non-availability of cervical cancer screening, detection and treatment services (Chawla et al., 2014).

The state-wide scale up of the Tamil Nadu cervical and breast cancer prevention initiative, which was initially pilot-tested in two districts between 2007 and 2010, demonstrates how political leadership combined with careful attention to program design, implementation and monitoring can rapidly translate to dramatic increases in access to services within a short period of time. Other states such as Sikkim show similar promise. Participants noted that leadership for cancer prevention in states such as Tamil Nadu and Sikkim emerged at least in part because of policymakers' awareness and understanding of the evidence on the emerging public health challenge of NCDs, including cancers, and on the availability

of effective prevention, screening and early detection approaches. In Tamil Nadu, a pilot program, which included a monitoring and evaluation component, yielded data on program outcomes that could be used to improve program design and advocate for scale-up. IS research is thus an important tool for promoting leadership and governance for cancer prevention and control.

Recommendations for IS Research on Cancer Prevention and Control

Our examination of the challenges and opportunities for promoting cancer prevention in India using an IS framework and the WHO's six health systems building blocks yielded a number of IS priorities (summarized in Tables 1 and 2). Community-level or "pull" priorities included the need to identify effective strategies to raise public awareness and understanding of cancer prevention, monitor knowledge levels, and address fear and stigma. Health systems-level or "push" and "infrastructure" priorities included dissemination of evidence-based practices, testing of point-of-care technologies for screening and diagnosis, identification of appropriate service delivery and financing models, and assessment of strategies to enhance the health workforce.

In 2012, over 1 million new cancer cases and 680,000 cancer deaths occurred in India. Nearly the same number of women in India died of breast and cervical cancers (137,695) as the number who died as a result of pregnancy-related complications (178,00) (Office of the Registrar General India, 2013; Ferlay et al., 2014). While efforts to reduce maternal mortality continue to make progress, increasingly, women will die of breast and cervical cancers in the absence of concerted public health action. Given the extent of available evidence, it is critical that cancer prevention and treatment efforts in India are accelerated. Implementation science research can generate critical insights and evidence to inform this acceleration.

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