

Breast cancer screening (BCS) in India: understanding challenges and opportunities by applying systems and complexity thinking

Abstract

Breast cancer is one of India's leading health issues, with the number of cases increasing year after year. This health threat has surpassed the incidence of cervical cancer, which was previously the leading cancer in the country. Despite the launch of a landmark nationwide cancer screening program in 2016, India recorded 1.8 million new breast cancer cases in 2019 with 90,408 fatalities in 2020, straining the country's health systems. These fatalities were estimated to be twice as high as in the United States, indicating low participation in these programs, making Indian women more likely to have insufficient screening and receive late diagnosis. Among the nation's many health priorities, coverage for breast cancer screening is extremely suboptimal, necessitating special policy considerations. This review highlights some key challenges and opportunities for advocating and employing systems and complexity thinking in cancer screenings, as well as how a holistic and culture-oriented approach could improve program participation and coverage. These considerations may eventually lead to improved health outcomes as well as sustainability and resilience in the country's complex socio-political eco-system.

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Irfan M Lone

Department of Medicine and Health Sciences, University of Ghent, Belgium

Correspondence: Irfan M Lone, Advance Master's Global Health, Department of Medicine and Health Sciences, University of Ghent, Belgium, Tel +32484217025, Email ifranmlon@outlook.com

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Setting the scene: introduction

This section highlights the concept and application of complexity thinking in breast cancer screening (BCS) in India and its potential to contribute to resolving challenges in the nation's sub-optimal coverage in the health and health care domain. Despite having 1.6 times fewer cases of breast cancer, the estimated number of deaths from breast cancer in India in 2020 was twice that of the United States.¹ This could point to the fact that Indian women are still not screened, and thus late diagnosis is common in the country. Even though the country has had cancer screening programs in place since 2016, only one in every ten women between the ages of 15 and 49 had ever had a breast examination. Furthermore, the survival rates of women with breast cancer in India are much lower than in other Asian countries such as China, Thailand, and the Philippines.^{2,3}

Indian Government's move to introduce BCS

Given the aforementioned factors, the Government of India launched a population-based cancer-screening program in 2016, under which all women over the age of 30 are eligible for regular breast, cervix, and oral cancer screenings. However, such population-based screening programs are intended to promote greater equity in access when compared to other health initiatives, such as opportunistic screening programs. However, the gradient of social inequalities in access to such programs is still visible and widespread.^{3,4} This creates unacceptable inequalities because disadvantaged populations are the most vulnerable, because they are also the ones who are excluded from such initiatives. This also applies to the fact that women from the affluent class have access to both public and private screening, while their less affluent counterparts lag far behind in such initiatives. According to the most recent data, India has no coverage for breast cancer screening. This could also

be since, even if women receive screening, it is either not reported correctly or older data is not updated in national registries.³

The following section will concentrate on visualizing systems that have both direct and indirect effects on breast cancer screening and coverage in India.

Social system and women's participation towards BCS

The social fabric of India is extremely complex and significantly complicated, which is reflected in the nation's health and health care plan. When it comes to health systems, particularly breast cancer screening, it is critical to understand how India functions as a society, community, or nation. There are numerous intervening systems at work, making achieving a specific health goal or priority even more difficult. To fully understand complexity thinking, it is necessary to map and visualize them. In this section, we will provide a brief overview and Mind-Map of some critical systems that are at the heart of our area of focus, namely, BCS Coverage.

Socio economic status: Women from low socioeconomic class or having low educational background tend not to seek care even after discovering a lump due to anxiety of facing family or societal rejection, fear of losing jobs, shame of discussing breast cancer within family, fear of undergoing surgery and its huge health expenditures, fear of dying due to the disease and the belief that the disease is incurable.⁵

Religion: Women belonging to certain religious groups tend not to opt for BCS. For instance, Muslim, unmarried and those with professional occupation were less likely to undergo clinical breast examination as compared to Hindu women, who are married and homemakers.^{4,6}

Caste system: Coverage to BCS is also influenced by caste system and social affiliation to groups and communities on which Indian system is forged.^{7,8}

Rural Vs urban residence: More than 70% of India's population lives in rural India which is a very significant factor for screening uptake, as it has been established that rural women are less likely than their urban counterparts to undergo breast screening.⁹

Paternalism and women’s autonomy: India is a strong paternalistic society where men have more say in important decision-making including health decisions having direct implication on women’s choices for opting or not for BCS.^{4,5,8}

Stigma and fear of screening: The word Cancer is still considered as a death sentence in India and oftentimes people tend to avoid or escape situations when they have to confront this word. This holds also for preventive or diagnostic measures.^{6,8}

Health literacy and awareness: Since more than half of India’s population resides in rural settings, with almost the same amount of people who do not even receive their primary education. This signifies large gaps among classes, groups and communities who differ also in health literacy. This is true for BCS, even though significant efforts on national and state level to raise cancer awareness have been made over the past decade.^{5,10}

Husband’s attitudes, support, involvement and awareness to BCS: Majority of Indian women only make health/decisions after being approved by husbands, men. This is true for even independent earning women who are qualified. Therefore, the husband’s role is crucial in BCS.^{5,11,12}

Comprehensive (health) policy: The Governance

Health insurance and social security: Less than 10% of India’s population have health insurance and for all health expanders including screenings, one must pay all out of pocket. This puts the Indian public in a great dilemma to prioritize health needs. Anything which is asymptomatic does not exist in India.^{10,13,14}

Health budgets and health spendings: Even though India has considerable investment for health budgets, yet due to its massive population and other health priorities (mostly infectious diseases and malnutrition) screenings are not given the push they deserve.³⁻⁶

Out of pocket (OOP) spendings: More than 80% of India’s population must pay from their pocket for simple to extensive health related diagnostics and treatment. This is due to non-existence of health coverage and health security in the country. However, the current national government is aiming to improve this.^{5,10}

Competing health priorities: India has many health priorities running in parallel from malaria, TB, malnutrition to other infectious diseases. This could be one of the reasons that screening programs were introduced so late and even after their introduction, most Indian regions lack the implementation.^{5,6,10,13}

Availability of health care professionals: To serve the gigantic Indian population, there is an enormous need for more health care

providers in the country and the ones who exist focus more towards core health problems.^{4,6}

Lack of proper campaigning: Even though national BCSP was introduced in 2016, yet the majority of Indian citizens are unaware of this, including clinical professionals. This could be due to inappropriate or even the absence of promotional campaigns for these screening programs nation-wide.^{4,5,10}

Role of Health care provider in BCS

Lack of education and awareness of BCS among clinicians: Despite huge emphasis on integrating educational programs on primary prevention, including BCS and screenings for other cancers. There is still a huge gap in the awareness among health care providers.¹⁵⁻¹⁷

Availability of screening guidelines: Since BCSP was introduced very recently in the country, there are still no standard guidelines from national or state level. This creates friction in the system wherein both clinicians and citizens over or underuse screenings.^{6,16}

Availability of screening professionals: In India, prevention is considered least of clinical attraction for health care providers. Even if it is, this would be mostly focused on infection related diseases such as Malaria and other infections. This leads to a significant gap in the availability of clinicians, who are also interested in BCS.^{18,19}

Health care provider’s time constraints: Given the gigantic population growth, increasing number of infectious diseases and sub-optimal number of health centers and health professionals in India. It is obvious that the existing clinicians must often work under time constraints to deliver their services. This is one of the key reasons impacting BCS uptake.^{4,6,13}

Interests of health care professionals: Even if India has enough number of clinicians, yet cancer screening is one of the least preferred areas in their clinical practice. This is because the screenings are generally considered “least fashionable” both by them and by the general public.^{10,14}

Attitudes of health care professionals: The attitudes and willingness of clinicians including nurses and para medical staff towards screenings in India are usually least favorite focus is more on intervention-based approaches than prevention.^{11,19}

Clinics/ health centers equipped with screening tools: Majority of the clinics/ institutions or centers equipped with latest screening tools are situated in big cities. This creates a huge urban-rural divide in India when it comes to accessibility of screenings (Figure 1).^{6,10,13}

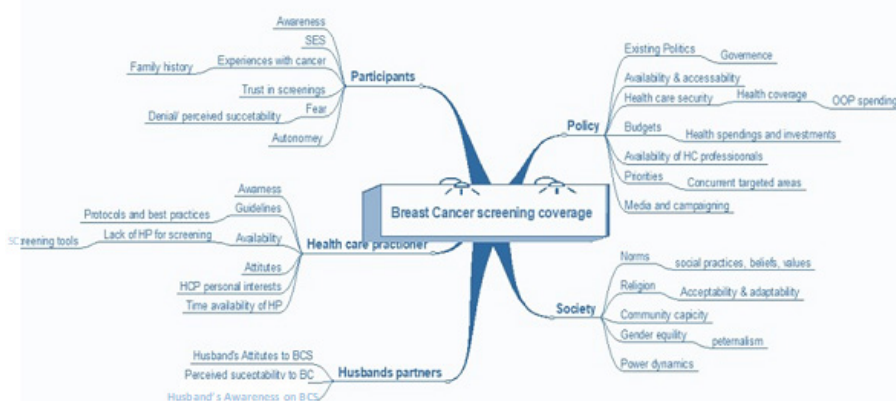


Figure 1 A Mind-Map diagram representing the different systems/ agents/ actors or determinants associated with BCS coverage in India.

Difficult, complicated or complex systems: What is in the name?

In its most basic form, a system is a collection of interacting or interconnected elements that follow a set of rules to form a unified whole. A complex system is one that is open and constantly changing, interacting with the environment and other elements. Even though the possibility of simplification exists, it is not always simple. Because complex systems include behavioral components, are nonlinear, open and dynamic, adaptive and self-organizing, and so on. Complex systems also include feedback loops, which may be other systems, subsystems, or elements that feed the main system either by reinforcing or balancing it. As a result, systems cannot be improved by removing only a portion of the whole. Thus, linkages and feedback loops must be always kept in mind, and the whole must be worked on. This is true for our BCS scenario in India, which includes a plethora of systems, subsystems, and other components. In this scenario, systems thinking will entail moving from observing events or data to identifying behavior patterns over time, and then surfacing the underlying structures that drive those events and patterns. Options can be broadened and more satisfying, long-term solutions to chronic problems can be created by understanding and changing structures that are not serving well in BCS, including the mental models and perceptions of stakeholders involved.²⁰

Detecting systems: The Iceberg approach for Breast Cancer Screening in India

To focus our discussion on BCS in India, we as system thinkers must first ask, "What is it about this problem that we don't understand?". To understand this, "the iceberg framework" in systems thinking must be considered in order to tell the full story of BCS. Clearly describing the problem from all three perspectives: events, patterns, and causes. In addition, we frequently assume that everyone involved in BCS (stakeholders, agents, or actors) has the same picture of the past or knows the same information. It is therefore critical to dig deeper into the situation and gather as much information as possible from all perspectives in order to ensure that all points of view are represented and that solutions are accepted by those who must implement them. When investigating the BCS India, it is critical to include people from various fields or functional areas to learn how different their mental models are from one another and what can be done to bring them together to begin system change.^{20,21}

In addition to the aforementioned elements, the context or situation of the problem must be taken into account. This is as a result that similar problems in different contexts may be solved using different or similar approaches (what is known or what is already existing, and how can it be improved). For example, there are numerous good policies with good intentions, but they frequently fail because the complexity of the problem is not considered.

In this way, even if they are temporary solutions to a problem, they lack sustainability and thus fail in the long run.

Why is it difficult to think in systems? Benefits of systems thinking in understanding BCS in India

Despite its promising payoffs in many areas, systems thinking remains one of the hardest approaches to apply. This is probably because, as humans we are naturally bound to think in a linear way. However complex problems are not linear, but circular and dynamic in nature. In this way, systems thinking broadens our thinking and helps us articulate problems in new and different ways, increasing the number of options for solving a problem. At the same time, systems thinking principles make us aware that there are no perfect

solutions; the decisions we make will have an impact on other parts of the system. We can reduce the severity of each trade-off or even use it to our advantage if we anticipate its impact. As a result, systems thinking enables us to make informed decisions. Systems thinking is also useful for telling engaging stories about how a system works. For instance, in our scenario of BCS in India, the causal loop diagram is an effort to tell this compelling story, in which we can clearly see different systems involved and their interaction with each other and with other elements.

System archetypes amid complexity: Decoding the storyline

Archetypes are recurring behavioral patterns in BCS scenarios that reveal information about the structures that power this system. They offer a method for decoding system dynamics in a variety of disciplines, scenarios, and contexts. In the set of common system archetypes around BCS, each has their own distinct causal storyline that can assist systems thinkers in seeing behaviors associated with the coverage to screening. These archetypes flow in more concrete terms once grasped by stakeholders and may provide insights into universal behaviors across different system scenarios which are linked to the bigger system of BCS. Thus, system archetypes have both a structure and a storyline, with structure being composed of several variables and feedback loops. One or more of which contains a delay that usually contributes to the unintended consequences of the behavioral pattern. Endogenous variables are those that are part of feedback loops that modify and are modified by other variables.

For a detailed understanding refer to CLD below. The eight most common system archetypes are:

- 1. Fixes that fail:** Even though a solution is rapidly implemented to address the symptoms of an urgent problem. This quick fix sets into motion unintended consequences that are not evident at first but end up adding to the symptoms.
- 2. Shifting the burden:** A problem symptom is addressed by a short-term and a fundamental solution. The short-term solution produces side effects affecting the fundamental solution. As this occurs, the system's attention shifts to the short-term solution or to the side effects.
- 3. Limits to success:** A given effort initially generates positive performance. However, over time the effort reaches a constraint that slows down the overall performance no matter how much energy is applied.
- 4. Drifting goals:** As a gap between goal and actual performance is realized, the conscious decision is to lower the goal. The effect of this decision is a gradual decline in the system performance.
- 5. Growth and underinvestment:** Growth approaches a limit potentially avoidable with investments in capacity. However, a decision is made to not invest resulting in performance degradation, which results in the decline in demand validating the decision not to invest.
- 6. Success to the successful:** Two or more efforts compete for the same finite resources. The more successful effort gets a disproportionately larger allocation of the resources to the detriment of the others.
- 7. Escalation:** Parties take mutually threatening actions, which escalate their retaliation attempting to "one-up" each other.

8. Tragedy of the commons: Multiple parties enjoying the benefits of a common resource do not pay attention to the effects they are having on the common resource. Eventually, this resource is exhausted resulting in the shutdown of the activities of all parties in the system.

Predictability amid chaos: finding the leverage points to lean on

Breast cancer screening, as mentioned in previous sections, is a very complex phenomenon to address in India. This is obvious due to the large number of actors involved, as well as the fact that many systems, such as the social system, belief system, and legislative system, are constantly interacting. This is in addition to the numerous health challenges that India is facing at the same time. When considering all the key parameters as well as health priorities and limited resources, BCS seems to be one of the pressing issues for the nation. Since so many elements are involved, the situation of BCS appears to oscillate between many points, if not infinite. In such a situation predictability becomes difficult to analyze. At the same time, it is important to be mindful of the carrying capacity of the bigger system, i.e., the bigger health system of the country when it comes to BCS.

Having said that, the system does occasionally reach a fixed point or fixed oscillation. When the pendulum reaches its resting point, system thinkers and policymakers working or involved in BCS in India must pay attention to these points. This is referred to as an attractor, which is a point towards which a system evolves, such as the final states of a damped pendulum. In the most basic terms, attractors may be the most useful concept in complexity science for understanding practical change-making. Understanding how an attractor works in BCS, actors can improve action and design more practical strategies in complex situations of screening policies, such as increasing public awareness towards screening, involving husbands/men to support women, positively shifting belief systems and reinforcing benefits and so on. Therefore, attractors can be seen as leverage-points to initiate changes in the system. In our example, of BCS in India, many attractors can be seen. These are points in a complex system where a small change in one thing can have a large impact on everything else. In the above-mentioned example, we can consider awareness of women or husbands towards BCS, as an attractor. Working on this loop can at least generate willingness in women and their husbands to access more information, explore options and discuss with clinicians about risks and benefits of opting BCS and/or not opting it.²²

Understanding strategies for system change: changing structure to change behavior

The insight in our causal loop diagram is that there is frequently a structural reason, or cause, for the emergent behavior within the BCS system in India. The primary goal is to recognize that the system's behavior is a result of how it is structured. This is beneficial because it allows change leaders to focus on creating better structures within the system rather than counterproductive attempts to control people's behavior.^{22,24} Hence, getting the entire system in the room is critical to achieving long-term benefits in BCS. This entails gathering all stakeholders with a stake in the change for BCS and bringing them together to co-create systemic (rather than single problem) solutions. For example, leaders, spiritual heads, district and province heads, women representatives, community workers, NGOs, courts and others will collaborate to find achievable and goal-oriented targets. With a mutual understanding in place, stakeholders can begin co-creating systemic solutions to BCS, which is otherwise considered an intractable problem. Furthermore, when solutions are proposed

and plans are developed, having the entire system in the room means that those with the authority to make decisions and direct resources are already present and bought in. This is especially important in structural transformations, which frequently have tight timelines and limited budgets to work with. Problems can quickly turn into solutions and then into actionable plans that have buy-in in this way, and all of the admin to get the entire system in the room will be worth the effort.

As a result, strategies for successful change in the BCS scenario in India will necessitate bringing the entire health care system into the room and identifying and exploiting leverage points. However, many of the parties or actors involved may show resistance as well. As a result, it is critical to consider everyone's viewpoint so that the decisions made benefit the most people, particularly those who are vulnerable.

Conclusion

Overall breast cancer screening is one of the complex challenges for the nation of India, which is currently battling the double burden of epidemiological transition. Even though a commendable progress has been made over the last decade, other health priorities still push cancer screening in the background. Despite the existence of promising strategies, medical and technological boost, modern India is still rooted to its cultural heritage, social norms and belief system, which also have an impact on health care, health decisions and health care involvement, including health screenings. Innovative approaches in policy and implementation for optimizing cancer screening in modern India must integrate these elements. A holistic and culture sensitive design to health policies and health systems must include and embrace all stakeholders as the co-creators of health. It will be fascinating to see how India shuffles its whole numbers and half-truths when it comes to breast cancer and how systems thinking will be a promising approach in saving thousands of lives from this disease's threat.

Policy recommendations:

- A holistic, culture-oriented approach with more momentum on community involvement, especially the vulnerable or hard to target groups.
- Integration of all available media channels, for policy dissemination and diffusion and to target wide range of populations.
- Liaising with community champions like religious heads, political figures and village heads to take up an active role.
- Women's education on cancer prevention, offered by women from the community.
- Decentralizing the points of deliver, example mobile clinics, camps etc. in rural India.
- Involving NGOs, Civil societies and other stake holders who are already working for women's health and empowerment.
- Prioritizing the needs of women and integrating them into policies.
- Involvement of academia to take up the active role in research, monitoring and evaluations.
- Mobilizing all the available local resources and pro-actively seeking assistance from other international stakeholders.

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Conflicts of interest

Author declares that there is no conflict of interest.

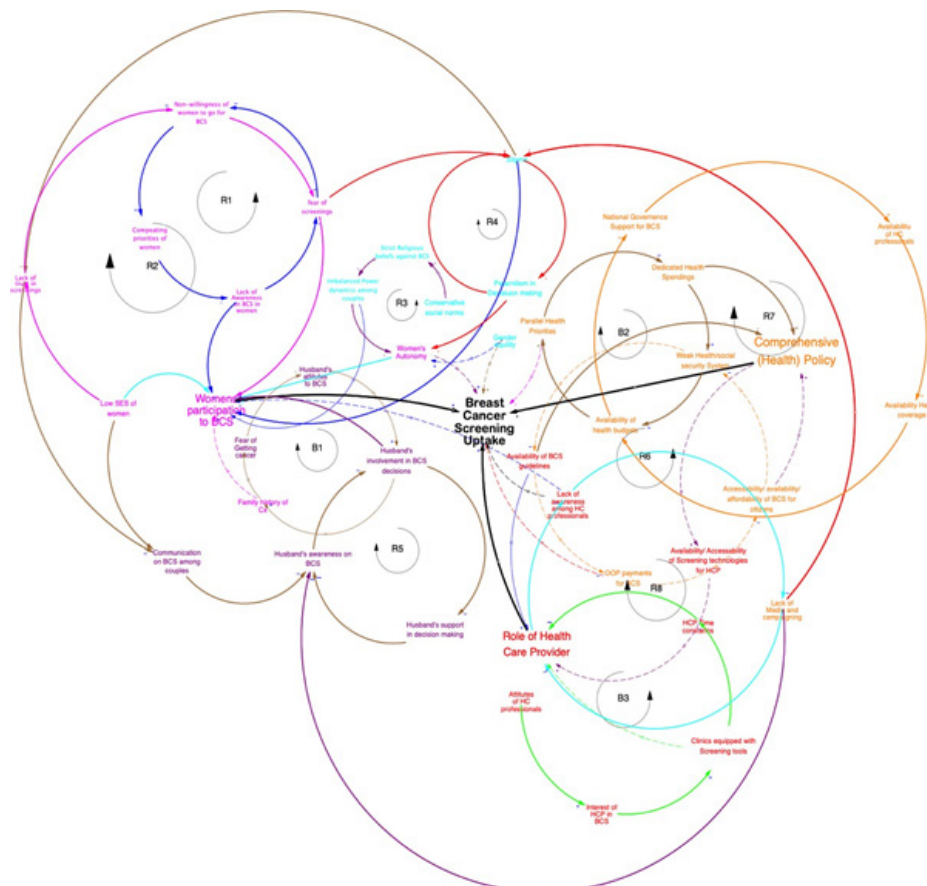


Figure: Causal Loop diagram (CLD) representing Breast Cancer Screening (BCS) scenario in India. The main concept/story is **Breast Cancer Screening Uptake**, in the center is surrounded by three key concepts of (a) *women's participation to BCS* (b) *role of health care provider* (c) *comprehensive (health) policy*, having a significant impact on it. All the concepts are either reinforced (R) or balanced (B) by underlying determinants, which also form loops that intern have significant implications on the main concept directly or indirectly.

Note*: one must be mindful of considering other systems, elements and determinants beyond the ones represented in this essay that have a direct or indirect impact on BCS in India.

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