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## Communicating Breast Cancer Awareness: Using the Health Belief Model to Develop Mass Communication Themes to Influence Early Detection Behaviors

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Communicating Breast Cancer Awareness: Using the Health Belief Model to Develop Mass  
Communication Themes to Influence Early Detection Behaviors

by

Srisai Kamakshi Ramya Harika Pucha

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
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with a concentration in Strategic Communication Management  
Zimmerman School of Advertising and Mass Communications  
College of Arts and Sciences  
University of South Florida

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## **Dedication**

I would like to dedicate this paper to my grandparents – my inspirational Ammamma Kota Vimala Devi and my genius late Thatha Kota Subramanyam. If not for the foundation you both set, if not for your humility; if not for your patriotism and your sense of dharma (duty), I wouldn't have been here doing what I do.

.

*“Haar jeet parinaam hai, koshish hamara kaam hai – Victory or defeat is merely an outcome, our duty, however, is to try.”*

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I would also like to take a minute to show my appreciation and gratitude to the five pillars of strength – my ever-believing Amma and Naanna - Sreedevi and Raman Pucha; my beloved Dugga Pinni and Raju Babai, and finally, my best friend and sister - Ragadeepika Pucha. I'm also grateful to my brother, Pavan Pucha, and my close-knit friends (too many to name) for being there at my corner at my darkest of times and supporting me through this whole process. They have all made this happen!

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## **Abstract**

Breast cancer (BC) is the most fatal cancer in India and has affected more than 1.3 million people in the year 2020 alone, making it a national public health priority. The reason for this alarming increase in BC incidences and mortality rates stems from a severe lack of awareness and the absence of targeted interventions. Considering the absence of a national level breast cancer awareness program, the following study sought to understand Indian women's preconceived notions about the disease and the available screening methods to contribute to future mass communication campaigns in India. The study used a pre-designed interview guide drafted using the socio-cognitive framework of Health Belief Model (HBM) to conduct 15 semi-structured interviews to understand these notions, namely the perceived threat of BC, the perceived benefits and barriers of engaging in BC screening – breast self-examination (BSE), clinical breast examination (CBE), and mammograms. The interviews also sought to understand Indian women's preferences on how they would like to be communicated to about breast cancer screening methods. The interviews revealed that there is an overall lack of awareness of risk factors of BC and the existing screening methods. Participants' lack of awareness led them to develop an optimistic bias about the disease. Moreover, while participants enjoyed the convenience of engaging in BSE, there were multiple factors in their daily and social lives acting as barricades to screening. This study proposed that a well-rounded approach to mass communications is much needed in effectively addressing the lack of awareness. Using visual



and audio channels of cinema, social media, and print media, Indian women can be communicated to about the importance of screening. However, participants trusted their medical practitioners and mothers to be the bearers of breast health-related information. The study concludes by proposing that mass communications should consider a wide range of target audiences; that is, besides the general population, the audience should also include medical practitioners and parents. A multi-level and integrated approach to designing mass communications is needed to effectively influence uptake in BC screening services.

## **Chapter One: Introduction**

According to the Indian Council for Medical Research (ICMR), about 1.3 million people were diagnosed with breast cancer (BC) in India in the year 2020 alone and the number is expected to go up to 1.5 million by the year 2025. Agarwal and Ramakant (2008) and Gupta, Shridhar and Dhillon (2015) recount that while these statistics are low compared to developed countries, the number of BC incidences are rising at an alarming rate. Moreover, the mortality rate of BC in India is even more alarming and needs to be adequately addressed as a serious public health concern (Curado et al., 2007).

Studies (Agarwal & Ramakant, 2008; Sathwara, Balasubramaniam, Bobdey, Jain, & Saoba, 2017) have credited the high BC mortality rates to delayed diagnoses, which affect long-term prognosis and recovery. Studies suggest that a patient's prognosis depends on the stage of cancer at the point of diagnosis, and for a cancer as aggressive as BC, it is highly recommended to have a confirmed diagnosis at the earliest stages (Hanrahan et al., 2007; Yabroff & Gordis, 2003). Hence, to make a difference in the mortality rates, we must begin by focusing on influencing early detection behaviors.

It has been found that lack of awareness and lack of screening programs are the primary reasons for late-stage diagnoses (Agarwal & Ramakant, 2008; Dey, 2014; Jones & Johnson, 2012; Jones et al., 2014; Sharma, Costas, Shulman, & Meara, 2012; Pati, Hussain, Chauhan, Mallick, & Nayak, 2013). Even in the year 2022, despite the rising BC incidence and mortality statistics, there

is still no sight of a national or regional screening program in India (Agarwal & Ramakant, 2008). It is suggested that awareness and education are the primary tools for ensuring early detection in India, and hence, are the solution for tackling the high BC mortality rates (Gadgil et al., 2012; Mitra, 2008; Sathwara et al., 2017). However, India's economic and public health realities, along with the current status of BC awareness, need to be considered to effectively implement awareness programs (Okonkwo et al., 2008; Xue et al., 2011). At the same time, awareness programs need to be articulated and communicated in a way that is informed by people's existing knowledge and perceptions about the disease and its screening methods to effectively influence desirable behaviors.

This thesis study employs the Health Belief Model (HBM) to gauge people's perceptions of threat toward BC and their perceptions of benefits and barriers toward engaging in early detection behaviors. HBM has been widely used to study breast cancer screening behaviors across the globe. This framework has also been used extensively to study the decision-making process behind women's behaviors for early detection of breast cancer (Calnan, 1984; Champion, 1985, 1993, 1999; Guilford et al., 2017) and cervical cancer (Aldohaian et al., 2019), especially for engaging in difficult decisions like oophorectomies (Herrmann et al., 2018) and mastectomies. HBM simplifies these decision-making processes for scholars, which further helps in designing behavior-change focused interventions/messages (Rosenstock, 1974, 1974; Rosenstock et al., 1988). Moreover, health interventions based on results from HBM-based studies have proven to increase the rates of breast self-examinations and mammography (Tuzcu et al., 2016).

Scholars suggest that people in India are blissfully unaware of their risk to BC (Gupta, Shridhar & Dhillon, 2015). Some studies also state that a few people even fear the screening or

check-up itself due to the stigma associated with BC. This fear can lead to non-compliant behavior in women, not approaching medical providers despite being aware of symptoms, and not following up on treatment after diagnosis (Pramesh et al., 2014; Sirohi, 2014). Moreover, lack of awareness and limited access to medical resources and information also act as barriers to approaching breast screening (Dey, 2014). While BC awareness levels have been thoroughly explored in western nations, it is still largely uncharted in Asian countries (Solikhah, Promthet & Hurst, 2019). India has continued to note the low levels of awareness (Agarwal & Ramakant, 2008; Dey, 2014; Gupta, Shridhar & Dhillon, 2015; Jones & Johnson, 2012; Jones et al., 2014; Sharma, Costas, Shulman, & Meara, 2012; Pati, Hussain, Chauhan, Mallick, & Nayak, 2013) while there is a gap in research that fails to truly address India's problem with BC and its limited screening uptake. More importantly, critical studies are yet to be undertaken to tackle the glaring lack of awareness with mass communications. However, being cognizant of current awareness levels is an important prerequisite to designing effective public health strategies (Gangane, Ng & Sebastian, 2015), including mass communications. This study attempts to fill this gap in Indian literature by investigating Indian women's preconceived notions about the disease and screening methods that are playing a considerable role in hindering early detection of BC. However, the study does consider that just knowledge of BC risk factors and screening methods does not always elicit screening behaviors. Hence, the study adopts an all-round approach to define messaging content and tone for mass communications.

Owing to the economic condition of India, clinical breast examination (CBE) and breast self-examination (BSE) are the most cost-effective and resource-effective screening methods for Indians to engage in early detection of BC (Duffy et al., 2006; Gangane, Ng & Sebastian, 2015;

Okonkwo et al., 2008). However, mammograms are still considered the gold standard for breast cancer screening. Hence, the study chooses to consider all three screening methods to gauge which method is perceived to be the most accessible.

In summary, this study proposes to use the HBM framework to study women's perception of threat toward BC and perceptions of benefits and barriers toward engaging in cost-effective BC screening methods in India. Finally, the study also proposes effective mass communication elements, like message channels, message content, and tone, to fruitfully influence Indian women into engaging in regular BC screening.

## **Chapter Two: Literature Review**

### **Breast Cancer in India**

Cancer management is a national priority in both high-income and low-income countries (Okonkwo, Draismar, der Kinderen, Brown, & de Koning, 2008). While cancer research has certainly taken far more priority in high-income regions of the US and UK (Okonkwo, Draismar, der Kinderen, Brown, & de Koning, 2008), low-income regions in Asia and Africa are just beginning to identify the importance of prioritizing socioeconomic and psychological aspects of cancer research (Sullivan et al., 2014). In India, a diverse and multiethnic South-Asian country, this research has important implications.

Cancer research has flourished in India over the past two decades to create a much-needed public health impact (Sullivan et al., 2014). The research objectives align with those of any other country: create awareness and influence proactivity; improve patient outcomes and prognosis; create affordable solutions for care and treatment, and, most importantly, reduce mortality rates (Sullivan et al., 2014).

Cancer research begins with collecting data about the trends and patterns of cancer incidence. In India, while there is no single national registry that accumulates and organizes this data, the National Cancer Registry Program (NCRP) - National Cancer for Disease Informatics and Research (NCDIR) of the Indian Council of Medical Research (ICMR) in Bengaluru organizes data collected by individual Population-Based Cancer Registries (PBCRs) and Hospital-Based

Cancer Registries (HBCRs) across the country (Mathur et al., 2020). While the data is still unorganized, the registries play an important role in gaining some control over the epidemic of cancer in India. In fact, it was only in the year 2020 that Mathur et al. (2020) first attempted to deliver a framework to organize and examine cancer-related data across 28 PBCRs and 58 HBCRs in order to assist policy planning and develop solutions for prevention and control.

The data from cancer registries across the country suggested that 1 in 9 Indians younger than 70 years would most indefinitely develop a form of cancer in their lifetime (Ferlay, et al., 2015, Mathur et al., 2020). Of all cancers, Indian women are most prone to cancer of the breast. Breast cancer (BC) is currently the deadliest cancer in India, amounting to almost 10% of all cancer incidences. 1 in every 29 women are prone to BC in India, and women in urban regions are more vulnerable to it. Additionally, because of India's relatively young population, breast cancer is more prevalent in younger women (Mathur et al., 2020). Agarwal, Pradeep, Aggarwal, Yip, & Cheung (2007) report that 26% of BC diagnoses in northern India were younger than 35 years.

While it is difficult to define a root cause of breast cancer, it is, however, pertinent to note the risk factors, apart from the obvious genetic component, that could lead to breast cancer. According to the National Cancer Institute (2016) in the United States, there are many external risk factors that put women at risk for breast cancer, including their age, alcohol and tobacco habits, diet, obesity, age at multiple life events including menarche, menopause, first pregnancy, number of pregnancies, lactation habits, and birth control preferences (Bernstein, 2002). Tobacco usage has been found to be the largest factor contributing to breast cancer in India (Ferlay, et al., 2015). Additionally, Indian women have recently been observed following "Westernized" lifestyles that include urban lifestyles and changes in fertility preferences, which also puts them

at a higher risk for breast cancer (Mallath, et al., 2014). Here, it is important to note that most of the risk factors are pertaining to individual lifestyles and habits, which means that prevention would need to begin at a behavioral level.

As the discussion moves to behavioral and habitual changes, it is significant to note a few statistics about incidence rates and mortality rates in order to properly converse about screening resources and practices. Breast cancer has been termed as a “burden” to India by many scholars (Agarwal & Ramakant, 2008, Ferlay, et al., 2015, Mallath, et al., 2014, Maurya & Brahmachari, 2020). Although the number of incidences in India is still lesser than that in developed or high-income countries (Mallath, et al., 2014), the rate of incidence is continuing to increase annually by 3-4% as compared to just 0.5% in developed countries (Green & Raina, 2008, Maurya & Brahmachari, 2020). Moreover, the death rate of Indian women is far more alarming than any other western country (Dikshit, et al., 2012; Maurya & Brahmachari, 2020). The discrepancy between the high mortality rates and relatively low incidence rates is primarily due to diagnosis at an advanced stage (Mallath, et al., 2014), which can be attributed to a lack of awareness and poor access to screening and early detection facilities (Agarwal & Ramakant, 2008).

### **Breast Cancer Screening in India**

Screening for breast cancer takes form in three methods - breast self-examination (BSE); clinical breast examination (CBE), and mammography. Mammography, which is the ideal screening method for the earliest detection of breast cancer, is not easily accessible in a resource-deficient country like India (Green & Raina, 2008; Okonkwo, Draismar, der Kinderen, Brown, & de Koning, 2008). Moreover, mammography isn't included in annual health check-ups or health plans and is usually provided only when requested (Agarwal & Ramakant, 2008), especially in



India where most healthcare expenditures are out-of-pocket in nature (Pramesh, et al., 2014; Reddy, et al., 2011). Hence, CBE and BSE are more accessible ways of getting screened for breast cancer. BSE is observed to be preferred over visiting a doctor for screening, and almost all diagnosed patients present with self-detected symptoms (Agarwal, Pradeep, Aggarwal, Yip, & Cheung, 2007). However, even with self-detection, 60% of Indian patients are still getting diagnosed at advanced stages of the disease (Leong, et al., 2010). Since the patients are mostly younger (Raina, et al., 2005), the cancer is far more aggressive with a higher chance of recurrence with a poor prognosis (Chauhan, et al., 2011). It is because of these late diagnoses that breast cancer is the most fatal cancer among Indian women (Dikshit, et al., 2012; Maurya & Brahmachari, 2020).

The problem of late diagnoses lies with lack of access to proper care, the general stigma around cancer and breast-related diseases, and, most importantly, lack of awareness (Agarwal & Ramakant, 2008). Even with the continually increasing incidence and mortality rates, India is yet to offer a national screening program for breast cancer (Mallath, et al., 2014; Sullivan, et al., 2014). Indian public health policy also needs to be modified to develop more awareness programs that effectively influence healthy early detection and screening behaviors (Mallath, et al., 2014; Pramesh, et al., 2014).

### **Breast Cancer Awareness in India**

As discussed earlier, most breast cancer risk factors are behavioral and habitual in nature, so there is a need to educate the population in order to bring about a change at a behavioral level. In order to do so, it's important to understand Indians' behavior with respect to how they approach healthcare and health decisions. On the other hand, it's also essential to know where

they already stand with breast cancer awareness in order to change what's ineffective and implement what's necessary for the needed change.

With an increasing trend in the number of breast cancer incidences in India, there is a necessity to look into improving breast cancer awareness. There is admittedly low awareness about breast cancer, and there has been little to no change in the levels of awareness of the related risk factors in the past decade. Agarwal, Pradeep, Aggarwal, Yip, & Cheung (2007) suggest that there is a high level of ignorance in India fueled by myths and misperceptions that create an illogical fear of the disease. This fear has been known to manifest itself in the form of stigma and/or ignorance (Cockburn, Staples, Hurley, & De Luise, 1994; Ellman, et al., 1989; Pramesh, et al., 2014; Sirohi, 2014).

India's diversity on the basis of socioeconomic status, religion, caste, and education provides more of a challenge with designing awareness programs and campaigns as the intersectional marginalities play a huge role in how the population receives the message (Okonkwo, Draismar, der Kinderen, Brown, & de Koning, 2008). These intersections of social identities and the lack of tailored interventions have only seemed to make ignorance grow and have influenced low levels of efficacy. Since the existing awareness is invariably accompanied by fear or stigma, there's also no compliance among Indian women in engaging in any kind of screening behaviors (Cockburn, Staples, Hurley, & De Luise, 1994; Ellman, et al., 1989; Pramesh, et al., 2014; Sirohi, 2014). Daniel, Venkateswaran, Hutchinson, & Johnson (2020) also state that this behavior is cultural in nature as opposed to geographical or economic after observing that Indian women tend to remain the least aware of breast cancer screening practices and advantages across the globe, even as immigrants in western countries like the US and Canada.

Studies focused on increasing breast cancer awareness in India have stated that an organized and multidisciplinary approach is needed to create an impact (Malvia, Bagadi, Dubey, & Saxena, 2017). This multidisciplinary approach should include awareness programs about symptoms, risk factors, and screening methods, conveying the importance of screening, increasing the availability of screening, and provision of treatment facilities (Gadgil, Roy, Sankaranarayanan, Muwonge, & Sauvaget, 2012; Mitra, 2008; Sathwara et al., 2017). It's also important to note that these efforts must be carried out differently for different groups of people taking into consideration the Indian diversity, as breast health awareness alone has not been a guarantee of compliance or healthy behaviors. There is also a need to address the myths and the stigma associated with breast cancer to eliminate overall indifference and ambiguity.

In this paper, the researcher seeks to understand BC-related behavioral nuances by relying on a socio-cognitive framework like the Health Belief Model to battle late diagnoses in India.

### **Health Belief Model**

The Health Belief Model (HBM) stemmed from Kurt Lewin's concept of the "life space", which divided an individual's life experiences into three categories, depending on the valence of the experience - positive, negative, and neutral (Rice, 2000; Rosenstock, 1974). Diseases or health issues, which form the fundamental basis for HBM's existence, are denoted a negative valence, and the framework helps explain people's efforts to eliminate the said health problem by zeroing in on their general beliefs and attitudes (Rice, 2000). The HBM was formulated by United States' public health experts as an effort to understand the American population's reluctance toward treatment or screening programs (Becker, 1974; Maiman & Becker, 1973; Rosenstock, 1974, 1974; Rosenstock et al., 1988). This framework has been consistently used in understanding health

behavior including health-seeking behavior, preventive health behavior, and even information-seeking behavior.

Essentially, the HBM is a conceptual framework designed to understand personal perceptions and beliefs toward a certain health problem or a health-related action, in order to design effective interventions or health promotion initiatives (Becker, 1974; Maiman & Becker, 1973; Rosenstock, 1974, 1974; Rosenstock et al., 1988). Its objective is to encourage healthy behaviors and actions of people who have an affinity toward developing negative consequences of a health issue (Becker, 1974; Maiman & Becker, 1973; Rosenstock, 1974, 1974; Rosenstock et al., 1988). It achieves this through HBM variables or constructs that help reinforce awareness of health-related risks, especially of diseases that are easy to treat if detected early.

The HBM constructs are as follows:

1. Perceived susceptibility refers to an individual's personal perception of how susceptible or vulnerable they are to a certain health condition (Becker, 1974; Maiman & Becker, 1973; Rosenstock, 1974, 1974; Rosenstock et al., 1988). In the context of this study, this would mean one's belief of how susceptible they are to breast cancer. Perceived susceptibility plays a significant role as a motivator for people to consider the reality of health issues in order to make the required change in their behavior (Rice, 2000).
2. Perceived severity/seriousness is personal perception of how the particular health condition would impact their lives, both personally and with regards to their health (Becker, 1974; Maiman & Becker, 1973; Rosenstock, 1974, 1974; Rosenstock et al., 1988). This, in the context of breast cancer, can include one's fear of death, fear of mastectomy,

or even fear of the cancer journey. Perceived severity also acts as a motivator for people to find health issues relevant.

3. Perceived benefits and barriers are the components that determine the likelihood of an individual to make the desired behavior change, while keeping perceived susceptibility and severity in mind. While influenced by personal beliefs, perceived benefits and barriers calculate the overall benefits of carrying out a certain action or making a behavior change. The positive factors (benefits) of a healthcare action that derive from perceptions of susceptibility and severity must overpower the negative factors (barriers) like costs, inconvenience, etc.; which ultimately determine the likelihood of an action being taken (Becker, 1974; Maiman & Becker, 1973; Rosenstock, 1974, 1974; Rosenstock et al., 1988).

4. Cues to action are recent additions to the framework and form a part of the extended HBM (Strecher & Rosenstock, 1997). This particular construct refers to an internal or external (Hochbaum, 1958) cue that triggers the desired behavior change. This could mean a mass media promotion or even a healthcare provider's recommendation.

5. Self-efficacy, as part of the extended HBM, refers to an individual's virtue with respect to following through with a health behavior change (Strecher & Rosenstock, 1997). This construct is the most important as it facilitates the understanding of people's willingness to actually engage in a certain behavior. For example, an individual with high self-efficacy may find no issues whatsoever with conducting regular breast self-examinations.

The Health Belief Model has been applied and used in the field of public health and health communication since it was first developed in the early 1950s. The framework was first used to understand preventive behavior (Haefner, 1974) in regard to tuberculosis screening, and has now extended to understanding behavior change, the validity of health educational interventions, and even self-care behaviors (Becker, 1974; Maiman & Becker, 1973; Rosenstock, 1974, 1974; Rosenstock et al., 1988). Within the topic of preventive health behavior itself, HBM has been widely used to study cancer screening behaviors across the globe. Having been widely used to investigate women's health behaviors (Tanner-Smith & Brown, 2010), the framework has been used to study the motivations behind women's behaviors for early detection of breast cancer (Calnan, 1984; Champion, 1985, 1993, 1999; Guilford et al., 2017) and cervical cancer (Aldohaian et al., 2019), especially while engaging in difficult decisions like oophorectomies (Herrmann et al., 2018) and mastectomies.

There has been extensive research on the development of the framework to make it a reliable model for public health advancement (Champion, 1984, 1993, 1999; Rosenstock, 1974; Rosenstock, Strecher, & Becker, 1988; Stretcher & Rosenstock, 1997). The individual elements of the model have also been thoroughly studied to understand their wide range of abilities in influencing behavior (Harrison, Mullen, & Green, 1992). Furthermore, HBM has been more relevant in studying and predicting women's health behaviors, specifically in reproductive health (Tanner-Smith & Brown, 2010), causing it to be the most invoked conceptual framework to predict women's approach to engaging in breast cancer screening. Champion (1985, 1993, 1999) has done tremendous research in the application of HBM to study breast cancer screening behaviors and developed a quantitative survey tool, which is still used to tailor interventions and study people's

breast cancer-related health behaviors. HBM simplifies these decision-making processes and factors for scholars, which further helps in designing behavior-change-focused interventions and messages (Rosenstock, 1974, 1974; Rosenstock et al., 1988). Moreover, health interventions based on results from HBM-based studies have been proven to increase the rates of breast self-examinations and mammography (Tuzcu et al., 2016).

Despite all the notable groundbreaking studies employing HBM in various health scenarios, the framework is not without its criticism. Carpenter (2010) concluded through a meta-analysis that HBM's variables weren't reliable enough to predict behavior. Another recent meta-analysis on HBM-based interventions supported this conclusion by suggesting that there is little-to-no contribution of HBM constructs on the actual working of interventions tailored to influence behavior change (Jones, Smith, & Llewellyn, 2014). Zimmerman and Verberg (1994) even went on to state that the HBM's predictive abilities were questionable, compared to the Social Cognitive Theory and Theory of Reasoned Action. HBM has been widely used in western scenarios since its initial development and has been blamed for fitting only a "White" standard (Tanner-Smith & Brown, 2010). HBM constructs, having been standardized (Weissfeld, Brock, Kirscht, & Hawthorne, 1987; Champion V., 1992, 1995, 1999; Champion & Scott, 1997;), assume an ideal scenario, which is hardly relevant for culturally complex and diverse countries toward the east (Ashing-Giwa, 1999).

To combat such criticisms, modifying factors were introduced to the model that act as mediating factors to the already existing constructs, thus increasing the clarity of predicting health behaviors (Stein, Fox, Murata, & Morisky, 1992; Hyman, Baker, Ephraim, Moadel, & Philip, 1994). These modifying factors include demographic and psychosocial variables (Tanner-Smith

& Brown, 2010) that help serve a complex and diverse population, hence developing into a usable model for a complex population. While these factors still don't help in contextualizing the personal/socioeconomic/cultural constraints that play a role in influencing women's health-related behaviors (Tanner-Smith & Brown, 2010), they're still an important aspect of the framework.

The Health Belief Model, however, proves to be a great conceptual framework to use in an exploratory fashion (Coreil, 2009) and has been employed in many qualitative studies (Ahmed, Fort, Elzey & Bailey, 2004; Ogedegbe, et al., 2005; Phillips, Cohen, & Tarzian, 2001). The model's clearly defined constructs, including the newly introduced factors, allow scholars to explore healthcare realities from the perspective of people by deep-diving into their perceptions of vulnerability and severity of diseases, and by also understanding the people's stance on how they weigh the benefits and barriers of engaging in essential healthcare behaviors (Coreil, 2009). Moreover, the qualitative nature of inquiry allows researchers to investigate between the lines of defined HBM constructs related to culture, society and psychosocial perceptions, allowing scholars to design informed interventions that employ elements that would influence desired health behaviors.

For the designed interventions to influence any behavior change, people must begin to acknowledge the seriousness of the disease and must consider themselves to be at risk of getting affected by the disease. Additionally, people must find the behavior change to be crucial enough to ignore the costs of engaging in the behavior, and most importantly, the people must be highly confident in themselves to effectively make the change (Champion, 1993).



## **The Research Questions**

This study draws on the extended version of HBM to inform mass communications. HBM's focus on health beliefs is especially applicable as it allows for communicators to design messages based on pre-existing beliefs and conditions governing the health behaviors of Indian women. Cues to action, in the form of mass communications, serve as tools for influencing behavior change. To be precise, they help in the likes of framing the health condition to be a real risk as informed by perceived threat; they help incentivize the behavior change as informed by perceived benefits; and they help battle the various barriers obstructing the behavior change as informed by perceived barriers. Mass communications, as informed by HBM, influence readiness to adopt a particular behavior by modifying health beliefs and tackling them head on. HBM's visualization of health beliefs obstructing a healthy preventive behavior is instrumental in realizing how health beliefs can be used as leverage to design effective mass communications. Moreover, HBM allows for an iterative process of developing mass communications between the communicators and the audience in that it allows for the audience's feedback on their evolving health beliefs to inform messaging.

HBM is starting to become more relevant in multicultural and diverse communities of the Middle East and Asia (Taymoori & Berry, 2009; Torbaghan, Farmanfarma, Moghaddam, & Zarei, 2014; Darvishpour, Vajari, & Noroozi, 2018) to study women's reproductive health behavior and influence preventive measures. In this paper, the author conducts a qualitative inquiry in a South-Asian country—India—through semi-structured interviews that rely on the Health Belief Model to suggest interventions that would effectively influence healthy early breast cancer detection behaviors.

Zimmerman and Vernberg (1994) asserted that even with the new additions to the HBM, the original constructs of perceived susceptibility, perceived severity, perceived benefits, and perceived barriers maintain the originality of the conceptual framework. In this paper, too, we conducted a qualitative inquiry relying on the original constructs of HBM. However, it is important to consider a few modifying factors that increase the usability of the framework in diverse scenarios. Drossaert, Boer, and Seydel (1996), Rice (2000), and Carpenter (2010) observed that perceived susceptibility and perceived severity were the weakest predictors of preventive health behaviors. The Extended Parallel Process Model (EPPM; Witte, 1992) postulates that susceptibility and severity variables are more reliable when considered with a modifying variable, namely, self-efficacy. Strecher, Champion, and Rosenstock (1997), on the other hand, suggest that the two variables are mutually influenced by each other, with the mediation of a third variable (Janz & Becker, 1984), resulting in increased reliability as a predictor of preventive health behaviors. This third variable, i.e., perceived threat, is a stronger predictor of behavior in comparison to susceptibility and severity. Since initial perceptions of the disease are important to be considered to suggest an informed intervention, our first research question is as follows:

RQ1: How do Indian women perceive the threat of breast cancer?

HBM is an important framework in public health research because it helps identify the exact pivotal trigger for behavior change (Green, Murphy, & Gryboski, 2020). It helps identify these triggers by investigating people's perceptions about the targeted behavior, which in this study's case is breast cancer screening. Perceived benefits and barriers are extremely important constructs of the HBM and the strongest predictors of BC screening behaviors (Tanner-Smith & Brown, 2010). Hence, we study these perceptions in two parts:

RQ2 (a): What benefits do Indian women receive from engaging in breast cancer screening?

RQ2 (b): What barriers do Indian women experience in engaging in breast cancer screening?

Finally, the objective of this study is to suggest informed mass communication interventions to effectively influence early detection of BC in India. These interventions can be classified as another one of HBM's constructs—cues to action, which along with self-efficacy, are the least researched element of the HBM. These cues tap into people's preexisting beliefs and perceptions and convert their underlying readiness for behavioral engagement into action. At the same time, the cues also attempt to challenge preexisting perceptions of barriers to essentially influence efficacy. In fact, Stretcher and Rosenstock (1997) clearly addressed the importance of informed cues to action by stating that the cues are highly reliant on perceived threat and perceived benefits. As the study focuses on cues to action in the form of mass communications, these cues can be addressed by determining mass communication channels, as well as influential messaging tone and content that would resonate most with the public. Hence, the final research question is:

RQ3: What elements should be considered in the creation of mass communications to influence breast cancer screening?

### **Chapter Three: Methods**

The goal of the study was to comprehend how Indian women perceive the threat of breast cancer, and the benefits and barriers of engaging in breast cancer screening. The goal was to use the learnings to consequently suggest relevant messaging elements for designing effective cues to action in the form of mass communications to influence early detection behaviors in India.

#### **Participants**

Given that the literature survey conveyed that Indians younger than 70 years of age and those living in urban areas were the most prone to breast cancer (Ferlay, et al., 2015, Mathur et al., 2020), Indian women between ages 21 and 50 and living in relatively urban regions were as participants for the study. As the study was to understand perceptions toward breast cancer and screening to influence early detection behaviors, participants who were never diagnosed with breast cancer were preferred. This ensured that the study specifically included the perspectives of women who were (or weren't) aware of breast cancer screening through ways that didn't involve a breast cancer diagnosis.

Upon receiving approval from the University of South Florida's Institutional Review Board (IRB) (See Appendix A for the IRB Document), a flier and a webpage were created using the web application Canva and Google Sites, respectively, to aid in the recruitment of participants. The webpage contained a description of the study along with information about informed consent, confidentiality, and voluntary participation. Additionally, the webpage also

included the Qualtrics survey containing the Informed Consent Form and a Contact Form for potential participants to fill. Snowball sampling was utilized and the flier, along with the webpage link, was shared with potential participants through WhatsApp and on Facebook and Instagram.

The Qualtrics survey, which was available for seven days, had 83 respondents consenting to the interviews- four respondents were under 21 years old, 51 were between 21 and 30 years old, 12 were between 31 and 40 years old, 11 were between 41 and 50 years old, and five were older than 50 years old. Of the 83 respondents identified as female, and two identified to have received breast cancer diagnosis. After considering the respondents through the lens of the determined inclusion criteria, it was found that only 56 respondents fell within the study criteria.

Out of the 56 respondents, 15 participants were selectively recruited based on age. Five participants were randomly chosen from each age group of 21-30, 31-40, and 41-50 years, and were contacted via email and WhatsApp to set up an interview date and time. Because of lack of responses on the interview from the age group 31-40, only four participants could be recruited from this age group, whereas six participants were recruited from the age group 21-30. The participants from the age group 41-50 remained to be five. The final 15 participants were then informed about the interview procedure. Since the participants were all residing in India and were in a different time zone, a Doodle poll was created by the researcher to avoid schedule clashes and confusion. The poll also helped keep track of the participants' interview progress and the interview times.

The interviews took place in the last week of August 2021 and were conducted over a 20-day period. The goal of the interviews was to attain "saturation" (Tracy, 2019); that is, the

interviews were to result in little to no new information through the answers. Interview saturation was attained at 15 participants (N=15).

## **Interviews**

Qualitative interviews, semi-structured interviews to be precise, were the primary method of data collection for this study. Qualitative interviews allow for the researcher to gain a deeper understanding of the participants' reasoning and motivations behind their behaviors (Rosenthal, 2016). Moreover, as the interviews were guided by a socio-cognitive framework like the Health Belief Model, they helped the researcher understand the participants' decision-making process with regard to screening methods (Herrmann, Hall, & Proietto, 2018).

In addition to helping gain valuable and detailed information, the semi-structured nature of the interviews allowed the researcher and the participants to have a natural conversation while staying on the topic. That is, the questions in the pre-designed interview guide were used intermittently to start a conversation or move between topics of importance. The structure of the interviews also helped with getting a good amount of information on a topic and tackling certain points that weren't foreseen by the researcher. The researcher was also able to probe the participants on new avenues of the discussion and ask follow-up questions as necessary.

The pre-designed interview guide assisted the researcher with asking the right questions. Conversations about breast cancer and breast screening were not comfortable for a few participants, so the questions were framed to earn the interviewees' trust and comfort. Additionally, the participants' views were heavily influenced by their childhood, exposure to health education, and schooling, and the guide helped with tailoring relevant questions to make

the participants as comfortable as possible. The interviews were predominantly in English, except one interview where the participant felt more comfortable answering the questions in Hindi.

Online interviews over video conferencing were preferred as the most convenient and cost-effective method during the difficult COVID-19 pandemic and to maintain quality of data collection (Sturges and Hanrahan, 2004). The interviews were conducted on Zoom at a pre-determined and convenient time for both the participants and the researcher. Zoom was a relatively convenient application for the participants, as they were habitually using it throughout the COVID-19 pandemic. It helped with face-to-face interviewing, which was necessary for gauging the participants' expressions and tone of voice on a sensitive topic like breast cancer.

The interviews began with a brief introduction by the researcher, who identified herself as a master's student at the University of South Florida. The researcher went on to explain the overall structure of the interview. After having taken verbal consent, the study questions were asked.

First, the interviewer attempted to break the ice by asking a few demographic-related questions and asking the participants to talk about themselves. To understand the overall perceptions toward BC, it was important to establish the participants' relationship and/or familiarity with the health condition. Hence, the first leg of the interviews was focused on family medical history, specifically in the context of (breast) cancer. The participants were also alternatively asked questions to gauge their level of breast cancer-related awareness and their understanding of the disease to gain an understanding of the basis of their views and perceptions. Finally, the interviewer began a line of questioning that involved an investigation into their health-related decisions with respect to screening, their convenience, and obstacles to engaging

in early detection behaviors. See Appendix B for a complete list of the interview questions. The interviewer followed relevant literature and course teachings by her thesis chair prior to designing the interview guide and conducting the interviews.

Moving forward, the questions intentionally followed the Health Belief Model (HBM) so that themes could emerge naturally as per the framework. The researcher also made sure to follow up on the answers to gain more elaboration and detail on the subject. Certain points made by the participants during the interview were probed further to make sure nothing was left misunderstood or unaddressed. Questions to understand the basis of the interviewees' views were added after the first two interviews. It was of the researcher's opinion that these questions could help in suggesting themes for designing interventions.

Finally, the interviewer asked questions about media messages surrounding BC, that is, if they had a memory of coming across BC related messages. The participants were probed further to gain an understanding of their opinions regarding the messages. The participants were also asked about their preferences of being communicated about the merits of engaging in BC screening. Here, the objective of the questions was to be able to list mass communication channels and messaging elements that the interviewees considered to be the most effective for them.

The entire interview process was open-ended but still intentional in nature to help the participants be free with their responses while giving direction to the study. Each interview lasted between 30 and 60 minutes, depending on how much the participants were willing to share. All the interviews were recorded on Zoom (video) and the interviewer's mobile phone (audio). The recorded interviews, except for the participant who preferred answering in Hindi, were run through a web application 'Transcribe' that provided a rough first draft of transcripts. The



transcripts were then proofread and edited along the way, using the audio recording to ensure nothing was missing, inaccurate, or miswritten. The interview with Hindi dialog was transcribed manually and translated to English. Each transcription took an average of 3.5 hours to complete and all the transcriptions were compiled to produce approximately 180 single-spaced pages. The interviewer also maintained detailed memos, which she noted down after each interview, to aid data analysis.

### **Coding and Analysis**

As mentioned earlier, the goal of the interviews was to achieve a point of saturation. The interviewer found that little to no information was contributed, at N=15, which is when she ceased the interview process.

The transcriptions of each interview were then analyzed through open, axial, and selective coding (Tracy, 2012). Since the study's interview guide was heavily reliant on the Health Belief Model, the researcher developed codes having a reference to the original HBM constructs. In the first step of the coding process, that is the open coding, the researcher assigned different words and phrases to a variety of ideas that were spread across the transcripts. Open coding allows the researcher to appoint labels to a multitude of phenomena and ideas expressed across the interviews (Williams & Moser, 2019). The goal of assigning these words was to ensure the label would capture the very essence of the said emotion or perception. For example, the participants' medical history, in the context of (breast) cancer, was labelled as "existent", "non-existent". The participants' generic beliefs about why they didn't believe they were susceptible to breast cancer were labelled as "*karma*" and "extreme optimism". The researcher also labelled precautionary measures taken by the participants to reveal open codes of exercise, diet, and sleep management.

The next step of coding, axial coding, allows the researcher to establish relationships between the open codes (Williams & Moser, 2019). For instance, barriers to screening like the participants' age, their time commitment, and their finances were coded under the category – "personal constraints". Codes of family issues and associated stigma were combined to establish the axial code of "Sociocultural factors".

Finally, the ultimate stage of coding, selective coding, allows the research to handpick and organize significant data that emerged in the axial coding in a thematic fashion (Williams & Moser, 2019). This stage allows for the data to take significant meaning and represents the outcome of the entire coding process (Williams & Moser, 2019). In this case, for instance, since the paper employs the Health Belief Model, the axial codes were segregated into respective HBM constructs of Perceived Threat, Perceived Benefits, and Perceived Barriers. The axial codes related to mass communications and messaging elements were organized under the selective code— "Mass communication elements". The final and detailed codebook can be accessed in Appendix C.

The researcher initially spent approximately 14 hours completing all three phases of the coding process. However, due to the complex nature of the conceptual framework, the labels were revisited and thoroughly verified six more times to make sure nothing went amiss, thereby spending around 50 hours altogether. The themes are presented descriptively in the succeeding chapters, with the help of flowcharts, under their respective categories of constructs.

## Chapter Four: Findings

The results from the qualitative study revealed that a multidisciplinary and multi-faceted approach is needed when designing mass communications to influence breast cancer screening in India. The following chapter answers the research questions framed in Chapter Two by laying out the different themes that describe the variety of Indian women's perceptions of threat toward BC and perceptions of benefits and barriers toward the targeted behavior, which is, engaging in BC screening.

As mentioned in the previous chapters, cancer research, particularly breast cancer research, has been gaining national priority in India for almost three decades now (Sullivan, et al., 2014) to combat the alarmingly high mortality rates and to lighten the heavy burden of cancer on the country (Ferlay, et al., 2015). India's fight against BC has always been directed at improving preventive healthcare and introducing screening services (Patel, et al., 2011). However, the progress has been very slow, either due to lack of prioritization by the government (Mallath, et al., 2014) or because of a deep-seated lack of awareness among the Indian population (Ferlay, et al., 2015; Mallath, et al., 2014; Mathur, et al., 2020; Mitra, 2008; Patel, et al., 2011). It has been observed that BC affects younger women more than anyone else in India aggressively (Maurya & Brahmachari, 2020); that is, younger women are presented with the disease at a far more advanced stage with poorer prognosis (Chauhan, et al., 2011).

Studies suggest that lack of awareness is at the core of the growing problem of breast cancer (Ferlay, et al., 2015; Mallath, et al., 2014; Mathur, et al., 2020; Mittra, 2008; Patel, et al., 2011). Despite the literature existing since the early 90s, there has been no development of a plan or change in policies to improve the reality of breast cancer in India. In fact, India still lacks a national movement or a national scheme to battle the lack of breast cancer awareness and breast cancer itself. To begin designing implementable mass communications aimed at influencing early detection, it is pertinent to know the existing levels of awareness and perceptions of Indian women toward BC and screening (Gupta, Sridhar & Dhillon, 2015).

This study aimed to examine Indian women's initial perceptions of BC through perceived threat, their perceptions of benefits and barriers associated with BC screening, and finally, mass communication elements for influencing early detection behaviors. A detailed codebook of the findings and respective sub-themes can be accessed in Appendix C.

### **Perceived Threat**

According to the researcher's codebook (see Appendix C), perceived threat, as a primary theme, is defined as "the extent to which an individual believes they are at serious risk of the disease."

The analysis revealed that 73% of the participants (n=11) initially reported that they never perceived themselves to be at any risk for breast cancer. Themes emerged only when they were probed further; however, that was also a task unto itself because of a generic lack of awareness altogether. It is critical to consider this lack of awareness as it begs to question if the participants' perceptions of threat are entirely guided by their lack of awareness. The interviews demonstrated that participants were candid about their lack of awareness. They expressed their limited

knowledge about BC and screening methods with appreciable honesty. At-risk participants, that is, participants with an existent history of BC in family, also admitted their lack of knowledge about their own risk. Participant (3) admitted that despite having a medical history of various diseases in her family including BC, she was “blissfully unaware” of how to act on her risk to the disease. Participant (1) also admitted that her knowledge about BC was limited to what she learned in her science class as young student. While participants’ candor about their lack of awareness was directly communicated, it was also noticeable when they admitted having limited understanding about screening methods. Here, it is important to note that most participants were generally aware about BSE but not about CBE or mammogram. Participant (4) communicated her limited knowledge about screening by stating that she had only heard about self-examination. Participant (7) was honest about having “zero knowledge” about any examinations. Participant (15) gave her opinion that, in her years as a medical professional, she rarely came across women who were well read or cognizant about BC or screening. The initial part of the interview guide, hence, was committed to establishing the participants’ familiarity with the disease, including the participants’ knowledge of the disease, their fears associated with the disease, and most importantly, knowledge of existing family history of cancer/breast cancer. Establishing the participants’ familiarity with BC was an essential step in deeply understanding the problem of awareness.

The analysis of the interviews revealed themes associated with both high and low level of perceived threat. Low threat, the first category, addresses the participants’ indifference to BC despite having a family medical history. The second category, high threat, elaborates on the fears and personal incidents experienced by participants that have contributed to a high level of

perceived threat. These emotions and reasons are important to consider, as they allow communicators to understand the initial psyche of their audience to tailor mass communications accordingly. A detailed classification of the sub-themes is illustrated in the Figure 1.

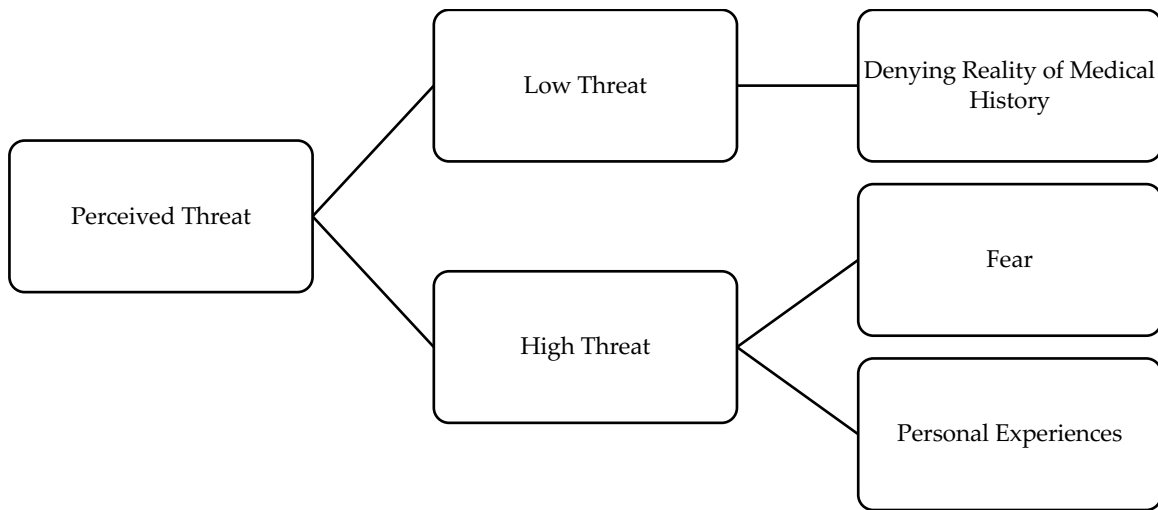


Figure 1: Sub-themes of ‘Perceived Threat’

The individual themes and their respective categories are articulated further in the following sections.

***Low Threat: Denying Reality of Medical History***

Family or medical history of cancer is a massive risk factor, especially in the context of breast cancer. This means that women with a family history of breast cancer have a genetic predisposition for BC and, hence, are at more risk. In a country where genetic predisposition is of utmost importance in the context of healthcare management, especially in the case of blood pressure, diabetes, and hypothyroidism, it can be assumed that it would hold just as much importance in the context of breast cancer. Only 4 out of 15 participants revealed that they had a family history of BC. While family history acted as an important determinant of BC risk and

affected one's perception of threat, it did not however guarantee a high perceived threat or even an intent to take action.

Two participants (7) and (9) with an existing family history of BC admitted that they did not perceive the disease as a threat to them. The participants, while cognizant of their medical history and the seriousness of the disease, believed it wasn't entirely worrisome. Participant (7) detached herself from her medical history and nonchalantly reported that she did not have a doctor, and has never visited a gynecologist. She admitted that she never considered revealing her family history to her doctors. She said,

“Actually, the thing is that I had this general knowledge that it (breast cancer) happens through genetics, but I never thought that yes, it is there with me also.”

For Participant (9), however, the genetic history was very real, but she believed herself to be too young to begin screening for BC. She said,

“Yeah, I mean, genetic (reason) is also there, so I may be prone to it.... I will want to be proactive after childbirth, umm just later in life because I don't think I need to now.”

Unfortunately, she doesn't state if this belief is because of family dynamics or because of her understanding of BC-related information she was exposed to.

Participant (5) with a family history of BC, on the other hand, admitted a high perception of threat. This, however, is because of experiencing a great personal loss due to the disease. Participant (5) admitted her “phobia” of cancer, as she lost her sister to BC. She elaborated,

“Her death made the cancer very real for me. I mean, unless you suffer, you don't understand the depth (reality) of the illness.”

Participant (3), also with a family medical history of BC, stated that she was aware of the seriousness of her history, but also recounted that she wasn't in the mindset to prioritize her breast health at the moment.

Despite the knowledge of their respective medical histories, there is a low perceived threat of BC. It was observed that knowledge of the history was not a strong enough reason to be mindful of their breast health.

### *High Threat: Fear*

Participants shared a deep fear of cancer, if not specifically breast cancer. This fear certainly plays a huge role in determining people's perception of the threat of BC and exists at various levels.

Firstly, there is the fear of the disease itself. There was a generic fear of cancer and not specific fear of breast cancer for most of the participants. They often associated cancer with death and believed there was no cure. Participant (7) stated,

"I don't think cancer is ever completely curable. So, if I get cancer, I know I'm a goner."

Other participants also described cancer to be depressing and lonely. They believed that the disease had the power to take over people's lives and replace it with just sorrow and depression. They even believed that the cancer journey, despite having support, is a person's solo journey. Participant (2) believed vehemently that a cancer diagnosis would be a solo journey for the patient. She stated,

"How much ever does anybody explain things to you or hold your hand? You know, any, anything else to comfort you? The ultimate, uh, thing that you go through, you have to go through alone."



Participants also reported a fear of the diagnosis and treatment. Intriguingly, this fear extended beyond death and some even admitted that death was more humane than the treatment. Participant (4) discussed that cancer is an ugly journey, physically and mentally. She also stated that she was fearful of the unapologetic nature of cancer itself. She stated,

“From the perspective of the patient, it’s surely stressful. The chemo, I mean. I have heard the process just makes you weak and it could make you puke and lose your hair.”

In addition to the fear of the journey, that is, the chemotherapy, a discussion arose around the topic of mastectomy. One participant (7) exclaimed that she couldn’t imagine herself without her hair and losing her hair would be the “absolute last straw” for her. While most of the participants were indifferent about mastectomy and dissociated themselves from the idea of losing their identity with their breasts, some termed mastectomy as “devastating”, as it was a huge part of their sexuality and femininity.

Participants were also concerned about how cancer would impact their family members. This concern, however, was predominantly noted among women who had kids. They didn’t want their children to grow up without a mother and were absolutely fearful of such possibilities. Participant (5) who was an extremely organized mother to two children, voiced her fears,

“I don’t want to put any trauma on my children. I want to be there for both of them individually throughout their lives. So I can fight the disease if I have the problem (cancer). I have the suffering, I have the medicine. I will go with the chemo, everything I can do, but you know, no one can fill that place of mine (of a mother) in their lives.”

She continued to explain that she witnessed her niece losing her mother, who’s also her sister, to BC. She expressed her sorrow that her sister couldn’t attend her own daughter’s

wedding because of the disease. She was fearful that if she too gets breast cancer, she would lose out on her children's important milestones.

While there was a discussion on the fear of financial consequences, participants did not particularly find financial consequences to be concerning. Most of the participants, owing to their middle to upper-middle class livelihoods, stated that they had health insurance and rainy-day funds to battle any medical issues. However, there was a fear of professional consequences; they were worried that a BC diagnosis would end their career. Additionally, they were also worried about their mental health consequences, claiming that it would plummet at the news of a diagnosis.

While there was one end of the spectrum that had a severe fear of cancer, claiming it to be "a monstrous disease" and "incurable", there was one participant (11) who was unafraid of cancer. She believed in facing her problems with a smile on her face and was okay with whatever life brought her. Citing the definition of karma, she stated,

"There is no point worrying about cancer. You do good, good will happen to you."

### ***High Threat: Personal Experiences***

Since some participants had close friends and family members who had been affected by different cancers, a high level of perceived threat stemmed from personal experiences.

Participant (1) stated that she was afraid of hospital visits because of her personal experience unrelated to BC. The trauma led to a fear of hospital visits. She spoke of her fear of hospital visits in a hypothetical event of BC diagnosis. She stated,

"I would not (go to a hospital so often), I would rather just not be alive then"

This fearful statement portrays the extent of people's fear of sickness, specifically cancer. This fear has the potential to be used as a trigger for increasing people's risk perception toward breast cancer because as far as the people are considered, they would be willing to go to any lengths to avoid the disease altogether.

Participant (2) also recounted her scary hospital visits with her father who was diagnosed with peritoneal cancer. She said,

"Because it is very scary because there, I mean, seeing my own dad, uh, succumbing to cancer is, uh, still a moment that I wouldn't want to deal with. So I know what cancer does to you. Any form of cancer, it doesn't need to be breast cancer can be any form of cancer. Right. I've seen what cancer does to people and I've seen the suffering."

Personal scares with breast cancer or even breast-related issues also had a great impact on people's threat perception. They used their traumatic personal experiences to guide their loved ones by communicating the tragic reality of the disease in an attempt to save them. This personal experience had such a great impact on their threat perception that they diligently took up regular screening behaviors. Participant (2) again recounted her recent scare with a mass on her breast and says how the scare "woke her up." She said,

"I was actually very careless about the examination before this (the incident) occurred. It was scary and I did not want cancer. I was so relieved it wasn't (cancer) and since then, I have religiously followed up with self-examination and I visit my gynecologist regularly too. I don't want my daughters to feel this fear, so I have been very open with them and taught them (BSE)"

Participant (5) was candid about her personal loss of her sister, who died of breast cancer. Having been empowered into becoming proactive about her breast health post her sister's death, she has vowed to help her daughter understand the importance of reproductive health. Participant (2) also supported this view based on her personal experiences.

Personal losses have made some participants vigilant about their health and have incorporated breast positivity and an open forum for discussing reproductive health in their parenting. Such personal experiences have shaped minds to take the BC epidemic seriously.

### **Perceived Benefits**

According to the researcher's codebook (see Appendix C), perceived benefits, as a primary theme, is defined as "the advantages an individual sees in their pursuit of the targeted health behavior."

The interviews revealed that less than 50% of the participants (n=7) had engaged in some form of breast cancer screening in their lifetime. Of these seven, only four participants had gotten a mammography done in addition to engaging in breast self-examination (BSE). The remaining 3 participants had only conducted BSE and no participant had ever had a clinical breast examination (CBE). Knowing and understanding the participants' perceived benefits sheds a light on what factors are the most favorable to engage in BC screening. These findings are important to either continue to assure the participants into pursuing screening services or to adapt systemically as per their favor. Coding and analyses revealed that the participants are looking for ease and the feeling of empowerment in order to engage in BC screening, hence, solely focusing on the screening method of breast self-examination (BSE).

Ease of access, as a sub-theme, addresses the participants' convenience with respect to engaging in a low effort method like BSE. Feeling empowered, the second sub-theme, addresses the participants' pursuit of independence and empowerment when engaging in BSE.

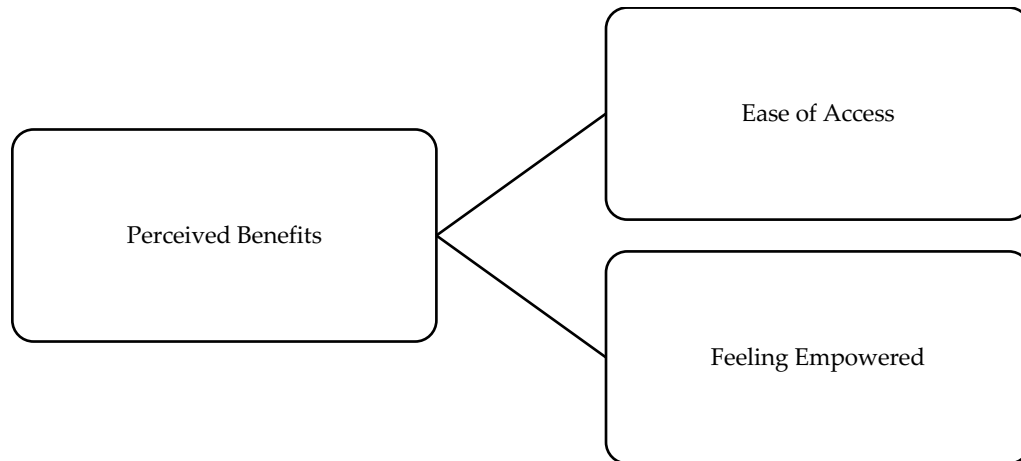


Figure 2: Sub-themes of 'Perceived Benefits'

These two sub-themes are further discussed in the following sections.

### *Ease of Access*

Participants were concerned about the convenience of engaging in breast cancer screening and agreed that BSE was the most convenient method as it required no financial commitment, travel commitment, and most importantly, it was the most accessible and the most time-saving method. One participant (1) said,

“The most convenient screening for me would definitely be self-examination because of the location I’m living in.”

Participants also found it convenient to engage in BSE over other methods for the sake of their own health, as it required zero financial commitment. This clause was incredibly important to the participants, as they weren't ready to have a conversation about their screening needs with their family members. This was a more prominent observation among the younger participants

who were still living with their parents. Other participants who were married and working were also inclined to engage in BSE as their heavy workload didn't allow them to take time off for a medical examination.

Individuals were more inclined to conduct BSE knowing that it did not require much training or information. Moreover, it could be a regular screening they could engage in since it did not require elaborate plans or appointments. It was an "everyday check". Participant (3) claimed,

"It's almost like an everyday check. So, I like that it's a lot more regular than a clinical one. It's a lot easier too.. I mean, rather than having to take an appointment and go to a clinic, wait in the waiting room and the time it takes."

Additionally, BSE was reportedly more convenient for the participants, given their daily busy lives, than a clinical examination and mammograms. They even liked that it didn't necessarily put the onus on just them and that their sexual partner, whom they would trust and love, would also be able to notice. Participant (12) stated that BSE was convenient for her, as she trusted her husband to notice any abnormalities even if not herself. She said,

"It has to be self-examination. I mean, ease of access, right? You can do it in the comforts of your home, at the luxury of your time... also, when you have a partner, you trust they will also be able to notice any drastic changes."

Finally, the participants agreed that BSE was their starting point for prioritizing their breast health. This is an important breakthrough, as any step forward is a leap in the right direction. Participant (14) said,

“I just never thought about it. Maybe self-examination is the way to go. I’ll learn to prioritize it.”

Participants were genuinely concerned about their breast health through the course of the interviews, yet were still hesitant about seeing a medical practitioner. BSE was the most convenient method of screening, in comparison to CBE and mammogram, and allowed them to prioritize their breast health without having to consult a doctor. Participant (4) stated that while she didn’t know how to conduct a self-examination, she was willing to learn and make time for regular examinations.

### *Feeling Empowered*

Breasts are a very personal and private part of women’s bodies, especially in a conservative society like India. With the rise in social media usage, Indian women are exposed to empowering content now more than ever. Participants believed taking control of their bodies and their health was an empowering journey. Many participants had already begun this journey by prioritizing their physical and mental health.

Feeling empowered was an important benefit to many participants for engaging in breast cancer screening. The benefits were again spoken of in context of BSE and mammograms, although mostly in the context of BSE.

A few participants admitted that they felt empowered by engaging in breast cancer screening. This empowerment was felt deeply by many participants, and they also claimed that they demanded a similar experience of empowerment in all their medical decisions. BSE, as a method of screening, requires individuals to be familiar with themselves and their body and, in the present day and age which is seeing a rise in female body autonomy, it is only natural that

they feel empowered. Participants believed familiarizing themselves with important information about their bodies was unshackling. Participant (13) said,

“I’m someone who actively pursues information. I like reading things online and papers, and I follow what’s needed. Information is power, and knowing my body also helps me feel a little calmer.”

For others, BSE was more about gaining control over their body and their health. This particular trait was observed to be a consequence of a personal loss to breast cancer. Participant (5), with the loss of her sibling to BC still fresh in her mind, was determined to make herself more proactive. She stated,

“Ever since my sister’s death, I diligently screen myself whether there’s something or not. It helps me to not feel helpless and I feel a little more in control.”

Younger participants in the age group 21-30 wanted to explore their bodies on their own before consulting a doctor or a nurse. They felt they needed to be comfortable and vigilant with their own bodies first before approaching a medical practitioner. Participant (4) believed that she should take up the responsibility of “listening” to her body first. She elaborated,

“I want to be in control of my body to the point that I want to be the first one to examine my breasts. For my own peace of mind, I would like to be the first one to know my body so well. If there were anything drastically wrong, I’ll have an official examination of course.”

A few participants emphasized their privilege and education. They believed that they were privileged enough to gain access to a wide variety of information and their education enabled them to make sound decisions about their body. Participant (13) stated,



“Our health is only in our hands, not in the hands of God. We have to take charge. We are well-educated; what’s the point if we don’t let our education inform us?”

Participant (8) also resonated with this notion and said,

“I definitely feel empowered by doing an exam on myself. I believe it’s a privilege to be able to get the needed information that serves our health and it would only be irresponsible to not use that.”

Participants who never experienced this kind of empowerment are now more than ready to invest in screening. Participants (9), (10), and (14) longingly admitted that they wished to feel such empowerment and control over their lives and their bodies.

Finally, individuals were inclined to engage in BSE for their own peace of mind. They put forth the logic that early detection would lead to better prognosis, and thought it was just more responsible to gain this peace of mind than worry about it in the future. They put forth the notion that this peace of mind was an empowering emotion in itself. Participant (4) assured her realization,

“Knowing that early detection leads to a better prognosis makes me feel calmer. So yes, I understand the importance of screening.”

Another participant (3), who believed in emotional manifestation of medical issues, also stated,

“I think information about my breasts, I mean, knowing everything there is to know about my breasts will help me with my state of mind and I think that will indefinitely help with my prognosis.”

As mentioned in the beginning of this section, breasts are a sensitive topic for women in India. Participants were shy talking about their breasts, but were also of the opinion that engaging in BSE would help them overcome their shyness. With the rise in discussions about feminism and body positivity, embracing the reality of breasts as parts of their body and not a sexual object will surely lead to a higher engagement in BC screening.

### **Perceived Barriers**

According to the researcher's codebook (see Appendix C), perceived barriers, as a primary theme, is defined as "the obstacles an individual sees or experiences in their pursuit of the targeted health behavior."

Considering that more than 50% of the participants had never undergone BC screening, understanding the obstacles hindering their screening behaviors was of utmost importance. An elaborate coding and analysis revealed three major categories of barriers: personal constraints, healthcare drawbacks, and sociocultural barriers (See Figure 3).

Personal constraints, as a sub-theme, addresses participants' limitations on a personal level due to factors like age, time, and finances. Healthcare drawbacks, the second category, articulates on systemic phenomena barricading Indian women's access to screening services by providing more insight on the nature of Indian healthcare and medical practitioners' approach to healthcare. Finally, sociocultural barriers, as a category, addresses India's sociocultural environment that presents itself as a barrier in various ways including family dynamics and stigma or taboo associated with screening.

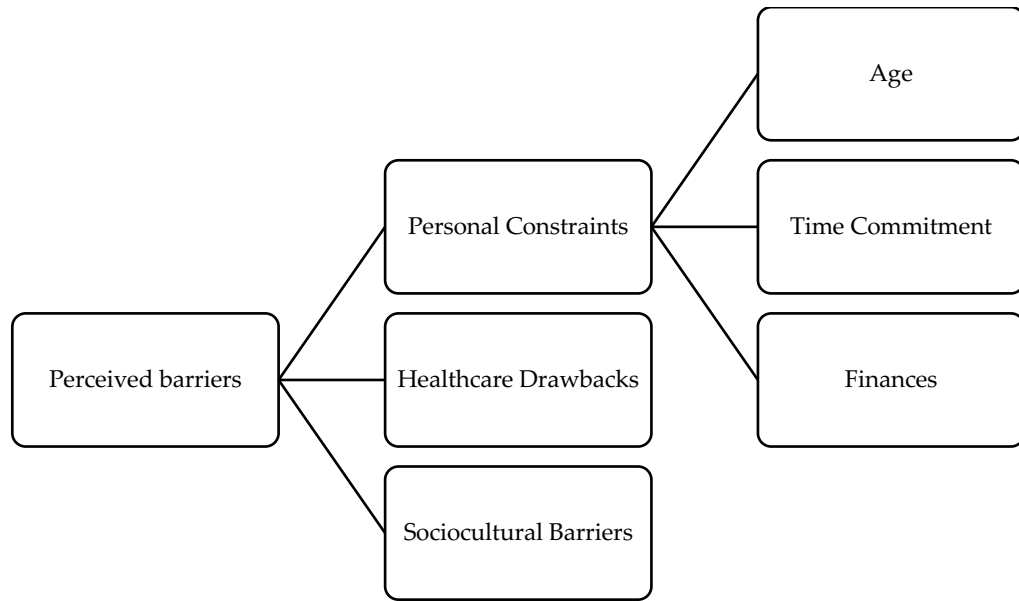


Figure 3: Sub-themes of 'Perceived Barriers'

The sub-themes are further elaborated in the succeeding sections.

***Personal Constraints: Age***

Age was observed to be a notable constraint to the participants, particularly to those in the early 20s and those in their late 40s, for completely different reasons. The younger participants were seen to be driven by their denial of being vulnerable to reproductive issues, precisely because of their age, and hence, didn't think it was too important to engage in any form of breast cancer screening.

One young participant (9) acknowledged her high risk of breast cancer because of her family history but considered herself too young to worry about it. She said she knew she'd have to worry about it in the future but for now, it wasn't a worry. She stated,

"I will definitely get screened for breast cancer when I'm older, but I don't think I'm in any danger now. I'm too young to even think about it."

Another participant (3) in her late 20s, who had an extensive family history of breast cancer, cited her aunt's advice and said she didn't see the need to get clinical screenings till she turned 35. She stated that even though the memory of her aunt battling BC was fresh, and while she feared her own risk to BC, she didn't believe she was yet at a point where it could be a worry. Moreover, she said that her personal life, her marriage at the point, took precedence over her health.

On the other hand, women in their 40s were admittedly accepting of their fate. They claimed that they resorted to age-related problems and that there was no point in getting screened— "Now I'm too old; what does it matter if I get screened or not?"

Even the younger participants claimed that their older relatives were rather "careless" and "submissive to their ultimate fate" because of their age. Additionally, they didn't think it was appropriate for someone their age to engage in breast self-examination. It's also important to note that age was considered a major factor in deciding whether to visit a doctor as well.

Another participant (6), in her 40s, made an interesting remark. She observed that she was able to engage in frequent BSE when she was younger, either because of her curiosity that came with adolescence and young adulthood, or because of her newly married life.

"It was definitely more frequent when I was younger. But it's been a while since our wedding, and we had kids. Now, it doesn't happen that much anymore, so yes, there's no self-examination whatsoever."

This remark gives an intriguing insight into how sex life plays an impactful role in the frequency of breast cancer screening.

Participants were citing their age, either that they were too young or that they were too old, as a reason for why they didn't engage in BC screening. These women weren't aware of the significance of age with respect to their vulnerability to BC, but assumed their age was reason enough to not be screened. While this factor also acts a reason for low perceived threat of BC, participants have been observed to assume age as a barrier.

### *Personal Constraints: Time*

Participants were reluctant to engage in breast cancer screening because it took a lot of time out of their day, especially for something that's more of a preventive measure than something that needed immediate attention. They believed they could invest the time they had into more productive activities over screening activities. Time was of the essence, especially for full time working mothers, and it was believed that a health issue was better dealt with if there were an actual problem at hand. Preventive healthcare wasn't a priority. Participant (3) stated,

“ So for me, I think the biggest obstacle would have to be the lack of time or more like the pain of setting up an appointment. There's also a lot of waiting time at the doctor, which is exhausting. Was it something more like if there were symptoms, then I'd make time (for the appointment) sure, but this is more preventative than addressing a particular symptom, so I guess there's a certain level of sheer lethargy.”

There is also no space for breast health because Indian families are preoccupied with “more important” health issues of diabetes and blood pressure. Since breast health isn't a part of most general wellness plans, BC screening gets pushed down the list of priorities. Indian families get their wellness checkups done as an entire family, which means they take a day off from work to get to their regular examinations. However, they would need to take an entirely separate

appointment for reproductive health issues, which the participants find they have no time for.

One participant (11) said,

“We are preoccupied with so many doctor visits for diabetes and blood pressure; there’s just no more time to even think about going to a gynecologist. It’s just not the biggest health priority, considering my busy schedule.”

All the participants agree that time is a huge constraint for them. One participant (11) put it succinctly, “A gyne(cological) check up is honestly the last thing on our minds. Put in the factor of time, it just gets pushed off the priority list.”

It is evident that Indian women are oblivious to the seriousness of the BC epidemic and with the current work culture and their household responsibilities, they are unable to prioritize their reproductive health. While most women are still able to prioritize their general health, their reproductive health has taken a backseat, which begs for an inquiry into the Indian healthcare system about serving women.

#### *Personal Constraints: Finances*

Since all 15 participants were from middle to upper-middle class families, there was no case of financial limitation on accessing the screening methods. However, the financial constraints take more of a sociocultural route. Participants are aware of the role financial independence plays in their health.

Participants in their 20s and even early 30s, especially the unmarried women, claimed that their financial constraints stem not from an economical cause but from the limitation of still living with their parents. They stated that their conservative family had a major say in their financial endeavors and even if not explicitly discussed, women were not comfortable explaining their

interest in securing their reproductive health. One participant (1) explained that she assumes it would be a difficult conversation to have with her mother, since her family has never been open to discussing reproductive issues. She said,

“I still live with my mother who keeps a close eye on my finances, so it’s just not that easy to set up a gynecologist appointment for myself. I will have to answer questions which I’m not comfortable talking to my mother about.”

Other young participants were dependent on their parents for financial support and didn’t want to stir up uncomfortable discussions with them, especially their fathers, who were the sole breadwinners for the family. They didn’t know for sure if they could approach their parents for such support.

Another participant (5), a financial advisor, commented on her acquaintances’ approach to dealing with financial constraints, “I know some women. They’re heavily dependent on their spouses for money, so they have no money set aside for their own health and since they have no money, they have no access to any doctors or medicines.”

Financial independence is a virtue for most women, but family and household responsibilities lead them to either give up their employment or they tend not to prioritize their finances for their health.

Some participants realize that mammograms are more expensive and are not able to afford it. Since healthcare is out-of-pocket expenditure in India and women’s reproductive health is not a part of most wellness plans, women are not willing to put in the extra money towards it. However, it is important to note that most participants were not engaging in BSE either, which is comparatively affordable and effortless.

### *Healthcare Drawbacks*

Participants believed that Indian healthcare was predominantly responsive and reactive in nature as opposed to precautionary, which they assumed was why they were never intimated about the importance of breast cancer screening. Participants who had access to regular gynecology checkups reported that the doctor never discussed breast health with them, nor did they ever conduct breast examinations. Despite falling in the recommended age group for regular mammograms, gynecologists hadn't intimated their patients about BC screening. Participant (12) said,

“My gynecologist never told me I should get screened for breast cancer, nor did she ever screen me herself, so I was never aware of such a precaution.”

Participant (2) called Indian gynecologists “pariahs” and remarked, “Of course they don't inform you about breast health. Also, no one goes to the gyne unless you are pregnant or have a urinary tract infection (UTI) so there's absolutely no scope of a breast examination, so no one asks because they just don't know.”

Participant (2) here brought up two significant issues. She stated that the healthcare system in India is such that women aren't able to access gynecological services and even if they can, the doctors do not educate them about their breast health. Gynecologists in India are mostly consulted in case of pregnancies, and the remaining reproductive health issues take a backseat.

Moreover, since Indian reproductive healthcare is largely responsive in nature, there are no conversations about prevention or screenings. Participants also admitted that their annual check-ups didn't include breast cancer screenings, as they're usually more expensive and clinical breast examinations aren't a part of general health check-ups.



Participant (5), a very proactive individual, said, “I had to be proactive. I have a family history (of breast cancer) so I straight up asked my gynecologist to screen me for breast cancer.... Before that, she never mentioned or talked to me about it.”

Participants (5) and (13) claimed that they had to take a stand for their health and didn't receive any education on their breast health till they advocated for their health themselves.

Additionally, the interviews revealed that most participants didn't have a gynecologist and rather consulted their “family doctors” for everything. It is important to note here that most of the mentioned “family doctors” are also homeopathic practitioners. Since the main expertise of these doctors lies outside reproductive health, participants hadn't been getting any medical attention about their reproductive health.

The interviews also revealed that Indian families tended to subscribe to alternative medicines as opposed to generic western medicine. There is a strong trust in homeopathy accompanied by a general distrust in western medicine, so it's safe to say that Indian families by default do not conform to western medicine's standard of precautionary healthcare. Participant (1) explained her mother's hesitance toward western medicine, that it was her opinion that western medical practitioners only cared about their business. She didn't trust such doctors and preferred to manage her health through more natural means. She explained,

“Hospitals and doctors only care about their practice and expanding their brand value. My mother hates going to allopathic doctors for this reason. Moreover, I have been using homeo(pathy) all my life, and it works wonders.”

Participant (1) also admitted that she had never experienced any homeopathic consultations focused on breast health. Homeopathic doctors are general doctors and don't use

the means of physical examinations for their diagnoses. While their medicines have been embraced by a majority of Indian families, they only tackle the symptoms they see and generally don't involve precautionary measures.

Other participants strongly remarked that they looked to medical doctors for direction, and they had never received any intimation that breast cancer screening was so important. Patients look to doctors for advice and expect to receive honest information about their bodies from them. One participant (7) declared she would only trust a doctor and not content on the internet about her health. She further explained that the internet tended to scare her with exaggerated information and gave value only to a doctor's advice. She stated,

“Uhhh no doctor has ever told me about it. If it (breast cancer screening) was so important, wouldn't the doctor recommend it?”

Participant (15), an army doctor, stated that doctors in India had varied approaches to patient care. While one doctor encouraged proactivity in their patients, others didn't approach an issue unless it was medically warranted. They believed too much information would scare their patients, as “they will hear the word cancer and start imagining the worst instead of the importance of regular examination.”

One participant (4) said, “I don't know, should I just ask the doctor? Isn't that a little too presumptuous?” Another participant (7), who supported this argument, retorted, “Why would I even go to a doctor if I have no problem? If they ask me why I'm there, what will I even tell them? I don't want to tell the doctor what to do!”

Indian reproductive healthcare is an ambiguous domain. Patients are unable to advocate for their health because of a general lack of awareness and because they don't want to overstep

with their doctors. On the other hand, doctors seem to be unsure of how to handle preventive healthcare with patients who come from culturally complex backgrounds. The end result in either scenario is that Indian women aren't receiving the information they need to make sound decisions about preventive health.

### ***Sociocultural Barriers***

The interviews revealed that social and cultural factors played a significant role, both directly and indirectly, in creating barriers for breast cancer screening among Indian women. India, being a culturally rich and a collectivist nation in general, brings along a multifaceted approach to making healthcare decisions. Social and cultural circumstances have created a severe hesitance in talking about breasts. This hesitance can be seen in the families' health care decisions and even in the national policy's approach to breast cancer.

One participant (3), who considered herself "breast positive", noted that while she was open to making a behavior change, things were different for her mother. She claimed that women 45 and above were more "careless" than anything else, and that they refused to listen to any reasoning because they seemed a little "squeamish" to talk about breasts with anyone.

Another participant (2), in her late 40s, admitted that women her age were hesitant to talk about breast health, and that it wasn't an easy conversation to have with her friends. She continued, "In fact, I avoid it. I can't impose uncomfortable conversations on my friends. What I can do, however, is make sure my daughters are comfortable and confident enough to prioritize their breast health."

The interviews also brought to light that family values and dynamics also play a huge role in determining women's approach to healthcare. 13 out of 15 participants remarked that their

limited (little to none) interactions with a gynecologist were probably because their mothers had never taken them to a gynecologist. While some participants, mothers mostly, proudly admitted that they were raising or going to raise their children to be more vocal about their reproductive health issues and questions, others who were still young and living with their parents admitted that their family dynamics made it extremely difficult to seek out a gynecologist.

Participant (10) claimed she came from an extremely conservative family. While she was keen on taking action on managing her reproductive health, her family wasn't. She stated that it was a cathartic journey for her to realize the importance of her health, and was sad that she couldn't do anything about it because of her conservative family. Stating that she wasn't sure what they'd think about her wanting to go to a gynecologist, she said,

"I consider myself to be open about my health issues, but I still live in a household where my openness is not appreciated."

She went on to say that she had to once save up money and visit a gynecologist secretly for a UTI because she was scared that her parents would question her virtue and ask uncomfortable questions about her sex life. She continued, saying that her lack of awareness about breast health and the fact that her family was uncomfortable having an open conversation about breast health could have contributed to her indifference to breast cancer screening. She continued, "It's a better option to go through all the headache of going behind their backs than to entertain their uncomfortable questions."

Another participant (14) believed she had inherited her female family members' indifference about her reproductive health. She didn't know her mother to talk about managing her breast health, so she didn't either. She declared,

"I believe indifference sort of gets passed through the generations."

Participants also revealed that their personal beliefs, which were learned from their family's or cultural values, also play a role in creating the severe hesitance toward getting screened. One participant (1) said, "Well, we believe in karma - Do good and good will happen to you. My mother especially is a strong believer. So, there's almost an eerie level of acceptance of fate, and they take on whatever comes to them."

She continued that this behavior of "accepting their fate" came with old age, that older women were able to submit to disease and old age, and strongly believed that if they did in fact get breast cancer, they probably "deserved it".

Another participant also noted that it would feel like she was "asking for breast cancer" if she were proactive about the screening because you would be "poking the hornet's nest".

Another cultural factor contributing as a barrier to breast cancer screening is the deep-rooted patriarchy prevalent in India and Indian families. The younger participants unabashedly admitted that patriarchy played a huge role in creating the existing stigma of reproductive health issues. One participant (4) stated, "I mean, patriarchy has taught Indian women that breasts are an inherent part of being a woman and breast cancer is usually associated with mastectomy." She continued by saying that her friends and family admitted they were afraid of facing a diagnosis and the resulting prognosis to a point of avoiding getting screened.

Patriarchy also made it difficult for women to advocate for their autonomy over their reproductive health within their own households. Some even avoided fighting for their autonomy in fear of living in constant dissonance. Other participants admitted that the female members of their family also felt a deep shame in asking for help because they didn't want to inconvenience anybody. This too is a result of patriarchal roots of family dynamics. Participant (1) empathized with her mother, that she had spent so much of her life caring for her husband and children that she didn't believe her health is important at all. She went on to give an example that her mother has always taken care of her family when they were sick, but she still has to do her regular household chores even if she's sick.

Participant (12) declared that it's hard to have breast cancer in India. She noticed her friends and family members with breast cancer never being comfortable sharing the nature of the cancer. She acknowledged her own initial stigma associated with the word 'breasts' and said that even when enunciating 'breast cancer' the first word is often uttered in a lower decibel. She continued,

"They wouldn't speak of it as cancer. They will acknowledge that as cancer. And again, it is very, very difficult for women to speak about that in a family setting where men are also sitting, because it is breast cancer and you cannot speak about it. Like you speak about cervical cancer or blood cancer."

There is a culturally driven stigma and hesitance associated with breasts, which has in turn affected access to reproductive healthcare in India. These barriers are prominent at the family-level of society and have spread to a community-level as well. Such barriers need to be

addressed and eliminated to ensure Indian women get the attention they deserve toward their breast health, among other things.

### **Mass Communication Elements**

According to the researcher's codebook (see Appendix C), mass communication elements, as a primary theme, is defined as "The elements to be considered for designing mass communication interventions for influencing BC screening."

Mass communication channels like print and television media have been extensively used to direct behavior change and influence positive attitudes toward health behaviors (Amezcuca, McAllister, Ramirez, & Espinoza, 1990; Cassell, Jackson, & Chevront, 1998). Determining the most appropriate channel is a significant prerequisite to designing persuasive messaging. Moreover, persuasive messaging involves messaging that allows the audience to "tune in" to the message content (McGuire, 1978, 1989). This kind of messaging involves a tone that is aimed to objectively motivate the audience to subscribe to a certain behavior. Simultaneously, persuasive messaging also involves determining the specific content that would allow the audience to resonate with the significance of the health behavior. These elements are developed iteratively while maintaining an open line of communication between the messengers and the audience to effectively achieve the behavior change (McGuire, 1978, 1989; O'Keefe, 1990).

A major part of the interviews was focused on establishing what elements should be considered in the creation and implementation of mass communications for influencing BC screening. Primary themes emerged suggesting preferable channels of mass communications, the favored message tone, as well as content that were considered the most influential to the participants. These themes and their respective sub-themes are illustrated in Figure 4.

The analyses revealed that participants valued both media and non-media sources for information about BC screening. The findings under this section are categorized into three themes – Mass Communication Channels, Message Tone, and Message Content. Mass Communication Channels, as a category, addresses how participants preferred to be informed about BC screening through media channels in the form of cinema, social media, and print media. Message tone, the second category, addresses the tone of the message that serves as a motivator for the participants. It explicates on the importance of considering people’s initial mindsets when finalizing the tone of the message, and how they feel about empowering messaging and fear-inducing messaging. Messaging content, on the other hand, articulates what the message should contain for the participants to be influenced into changing their behavior with respect to screening. The interviews reveal that participants wish to be informed and educated about BC and the screening methods, with an emphasis on the importance of early detection, and they preferred to receive their information from their doctors and mothers.

These themes are further elaborated in the succeeding sections.

#### ***Mass Communication channels: Cinema***

Participants expressed that cinema has played a significant role in learning about healthcare, physiological health and otherwise, by exposing them to a multitude of health conditions and society’s response to these respective conditions. Taking examples of Bollywood movies like *Taare Zameen Par* (on dyslexia), *Dear Zindagi* (on depression), *Paa* (progeria), *Shubh Mangal Savdhan* (on erectile dysfunction), one participant (14) explained,

“We learn so much from our movies about medical stuff. There are so many female oriented movies now that have stirred up important discussions.”



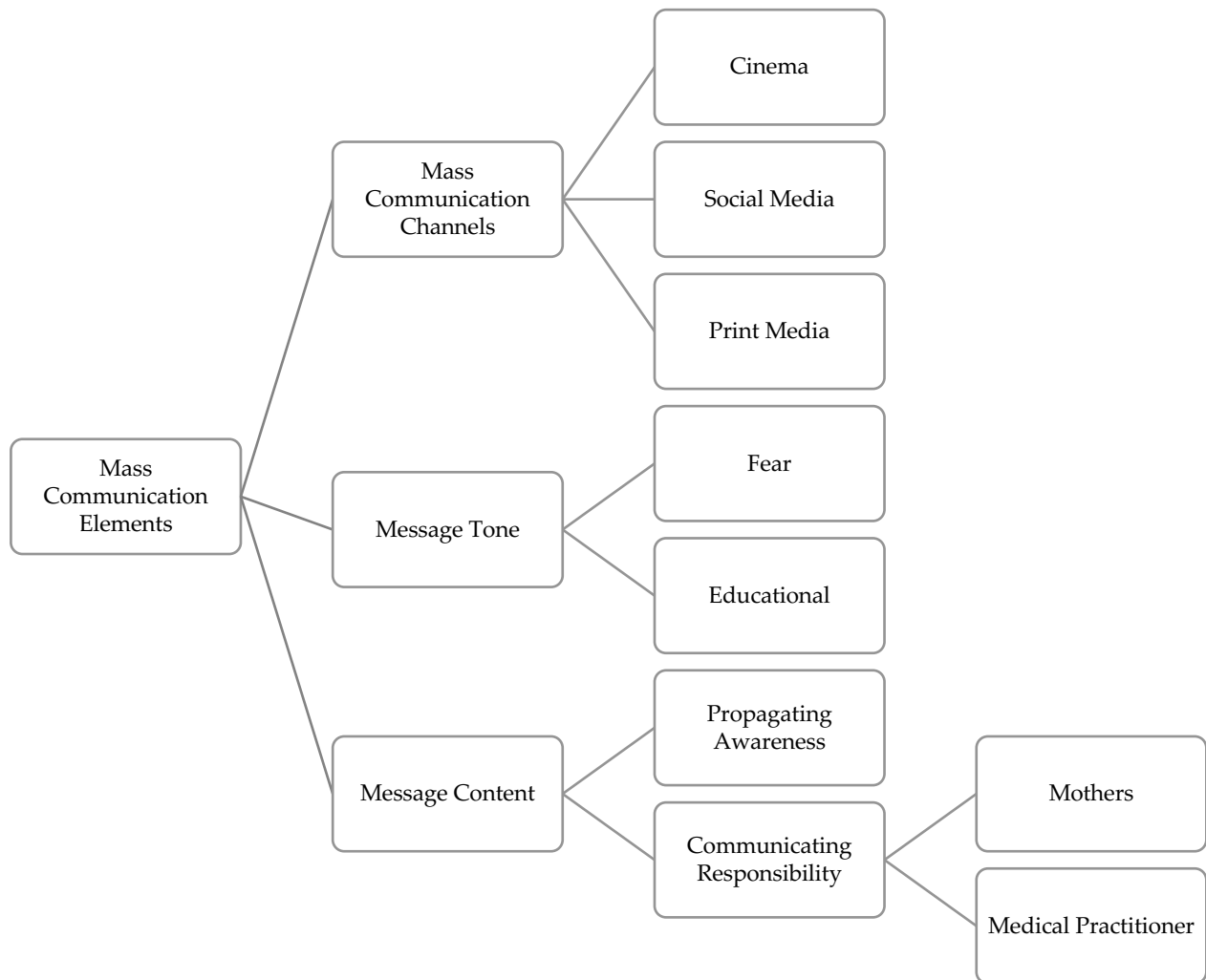


Figure 4: Sub-themes of 'Mass Communication Elements'

She explained further that if there's a movie, even a short film, showcasing female friendships in venturing through breast cancer awareness and embracing screening services, there could be a positive outcome in influencing Indian female minds.

Cinema is widely enjoyed by the Indian audience and in recent years, there has been an increase in commercial movies about social issues that needed to be discussed and destigmatized.

Participant (5) confidently said that while people might even stop watching TV, cinema will always remain a part of the Indian culture. Moreover, Bollywood is spread across the country, and even regional movies have started attracting audiences across states. She further said,

“We have Bollywood having more contribution in socio-cultural-economic development than any other industry.”

She further stated that Bollywood or the cinema industry in general should take advantage of their large audience numbers and work on educating women about their breast health. Cinema, she pressed, can help identify health issues and also train women in whom to approach and what questions to ask.

Participants (1) and (12) supported this view by taking it a step further and stating the influence of celebrities on the Indian audience. They stated that celebrity influencers from the cine-industry who are currently in remission after having faced BC would be excellent ambassadors to push breast cancer screening. They even named the celebrities who would be a perfect fit for the mission for different age groups. For instance, participant (1) gave an example of an Indian cricketer who was the spokesperson for no-smoking messaging across cinema theaters, stating that it was because of his constant presence in such messages that she automatically associates cancer with smoking. She went on to suggest an esteemed Bollywood actress who would make for an influential ambassador for the older generation. She stated,

“I think, um, somebody who has a better chance is probably a Bollywood actress from an old Bollywood actress. Who's probably in her fifties, mid fifties and sixties now. Okay. Somebody like that speaking, you know, calming, but commanding voice I think would, would have an impact on them.”

Participant (13), on the other hand, explained how there are Bollywood celebrities who were vocal about their breast cancer from the very beginning. She believed they would be excellent influencers in media for normalizing breast cancer talk and in turn, influencing Indian women to subscribe to regular BC screening. She explained,

“Maybe like things (messaging) from Sonali Bendre and even Ayushman Khurana’s wife, uhh Tahira Kashyap. I even read it during her cancer journey. That was very, very nice. She, all these women who are cancer survivors. Uh, they spoke about cancer in a new light. They spoke about how it is. So I feel real survivors, real people. They need to give, have an always on communication and put it out through real life experiences, not just, uh, how, uh, usual advertisements or marketing has done. You don't have real people. So I think both Sonali and Tahira are hit over breast cancer messaging. Yeah. So that journey was very, very inspiring.”

She went on to explain how these celebrities represent strength and confidence despite adversity, and believed this narrative was important, as opposed to the battered cancer survivor image.

Participants were also cognizant in recognizing the role of Indian cinema in stigmatizing breasts as a topic of open discussion. Participant (9) shared her frustration that Bollywood is a major culprit in making breasts a restricted topic of discussion. She stated,

“There are these item songs and movies that sexualize breasts overly. That should come down. In a way, by oversexualizing breasts, you're sexualizing all women and an important breast-related disease gets lost in it.”

Another participant (12) supported this statement by declaring that because of such oversexualization of women through item songs and movie content, women with breast cancer can't even talk about it with their family members. She went on to say that if a woman has breast cancer, she can't say share that her cancer is in her breasts as opposed to being open to sharing about cancers in other body parts.

However, all participants agree that cinema has an important role to play in India's sociocultural development, especially in the context of sensitive issues like BC. Participant (2) gave her opinion that cinema should start with talking about breasts first before anything else, as it would prepare the audience for a more mature discussion about breast cancer. She stated,

"If we can't talk about breasts, what would the movie even achieve. First, normalize breasts, then we'll see next."

The participants' statements strongly support the use of cinema as means of communicating important information about BC and influencing BC screening. However, the implementation of such a project should be done with utmost caution and sensitivity, and the movie-makers must be prepared for some backlash from the audience when taking such a bold step. Moreover, a good first step would be to reverse the damage already done in the past few decades. This begins with destigmatizing breasts in order to be able to open discussions about breast-related issues.

### ***Mass Communication Channels: Social Media***

Participants expressed that social media was a great outlet for receiving information about BC screening. They even claimed that social media exposed them to a variety of issues, and kept them up to date with current health issues and the necessary steps to take. With India's youth

being engaged on social media, social networking applications like Facebook and Instagram become an excellent space for sharing critical health-related information.

Younger participants like (1) and (10) stated that they were the most active on social media over any other media. Stating that she was very active on Instagram, participant (10) believed that she would benefit most from social media messaging. She went on to say that she tried to follow “good” and “educational” women’s pages and influencers, and she learned a lot through her exposure on social media.

Participant (1) claimed that she had read “wearing loose bras” was one of the risk factors for BC. While she didn’t remember the specific source of the information, she said that she was most likely to have come across the information on Instagram as that’s where she spent most of her time.

However, it’s important to note that social media was iterated as the most preferred source of information by the younger participants in the 21-30 and the 31-40 age group. Participant (5), who was in her 40s, stated,

“See, these messages will help young population, not ours. No one (our generation) sees, no one wants to see. It’s hard to say if FB, Insta will help”

Participant (7) also claimed that while she did come across relevant information on her social media feed, she didn’t feel such messaging was practical. She also believed that health-related information was often exaggerated to scare the consumers. She said,

“So, uh, largely I found, whatever information is there on the internet has stressed me more than what the problem actually had been. The problem was very minor, used to be

very minor and, uh, the symptoms, the, uh, diagnosis, et cetera, whatever given in the internet is very elaborate sometimes unnecessary.”

On the other hand, participant (3) believed that social media was an excellent platform for sharing information about BC screening. She cited elements of social networking sites like visual entertainment, and declared that visual elements could be wonderful tools for propagating the BSE method and the importance of screening. She went on to say that the younger generation preferred quick communication and were more attracted to clever visuals and graphics, and social media like TikTok and Instagram could be used to add in some educational content amidst entertainment for the “doomscrolling” consumers. Mentioning a couple of noteworthy influencers, she stated,

“I would think a TikTok with the one somebody talking would be excellent. Like why does it have to be like mindless entertainment? But not that that's bad. I'm not judging it.... We listen to @dr.cuterus and @mayasamma (influencers) talk about sexual health. We share it. So, it's turning entertainment into education. While we're doomscrolling, why not get educated right?”

She continued that Instagram would be a better alternative to TikTok on account of the TikTok ban in India. Participant (8) shared participant (3)'s enthusiasm for the visual elements by stating that she learned how to conduct a BSE through YouTube videos. It was hence observed that the visual and graphic aspects of social media were convincing factors in preferring digital media as a source of BC screening information.

Participants also claimed that social media is an exceptional tool for forming communities. Participant (1) explained that she and her close-knit friends used Instagram as a tool for checking

in on each other's mental health. She further stated that it was because of this constant checking in that she was able to educate herself about her mental health, and that it started important conversations that were emotionally helpful. When asked if she wanted a similar scenario for BC screening, she agreed that it would be helpful.

While most participants were partial to Instagram, Participant (14) on the other hand, iterated that a platform like Facebook would help provide support groups for women where they could learn to ask important questions about their breast health without feeling conscious. She stated,

"Female friendships are safe spaces and uhh Facebook is amazing in providing such groups. I think, well, it's important that the women know it's okay to ask questions, to feel curious. I don't think a lot of women do, so that should be communicated."

Participant (8) also declared that Facebook should notify consumers about BC screening drives nearby, as events.

However, social media as a preferred communication tool wasn't without its criticism. Participant (7) believed that social media messaging, especially about BC screening, wasn't practical. She stated,

"Sometimes, uh, I have seen, uh, like, uh, there are some pages that I follow on Insta and Facebook, about feminine issues. So a lot of times, uh, advertisements come there, like how to examine yourself, what symptoms to see. So, I keep on coming across these things, but, uh, if I say so, um, how practical that is to follow it very hard. Like if you're scrolling, you just see, and that is there in the mind. But in reality, how often I check is very few."

She explained that social media was largely about mindless scrolling to her and was doubtful of its efficacy. Participant (5) also didn't trust the efficacy of social media, especially for older consumers. She commented,

“See, these messages will help young population, not ours. No one sees, no one wants to see. It's hard to say if FB, Insta will help”

Participant (12) was also skeptical about social media and iterated that India's digital penetration was quite low. However, she agreed that social media was a great starting point. She stated,

“People are talking about certain things, but yes, it'll only impact a very, very minuscule, uh, population, especially in a country like India, because the digital penetration itself is so low. So yes, we have to go via a 360 approach, but social media can be the starting point, which is the tip of the iceberg.”

#### ***Mass Communication Channels: Print media***

Print media, via the likes of newspapers and magazines, has been losing its popularity since the rise in social media engagement. With news and literature being digitized, print media is hardly used for marketing or communications. However, in a country like India, where different groups of people are exposed to and prefer different platforms of media, print media remains an important source of information. Through these interviews, however, it has been observed that print is not the most popular media. Most participants (n=11) did not mention the use or relevance of print media in their respective lives. However, it has been observed to be the first source of information about BC and BSE for some participants.



Participant (14) stated that she used to come across BC related content in health columns of a regional newspaper, especially on women's day. She added that the newspaper used to have a specific column for women's health, and they helped keep her informed about various women's health issues.

Participant (6) mentioned a famous women's magazine, Femina, where she came across BSE for the first time. She stated that the magazine was very thorough and frequent in publishing about self-evaluation, and often included visuals about the method. Participant (4) also remembered a similar magazine with diagrammatic explanations and iterated that while she didn't remember the exact content, she developed a curiosity about BC screening.

Participant (3) provided the most insightful details about the magazine. She praised the magazine for providing bold information about sex and reproductive health issues. She described the magazine as having special sections about sex and reproductive issues, where a gynecologist would publish answers to anonymous questions. She stated,

"I mean, I used to find it incredibly funny and weird, but now as an adult, I realize what a safe space that was. It was kind of like checking in with your anonymous friends. And, women anonymously talking about their issues that they cannot share with anyone in a magazine that's targeted toward women? It must have created such solidarity ya."

She went on to state that this "solidarity" is "gone" for the older generation. She explained that magazines have become almost obsolete and hence, the previous generation doesn't have a chance to have their questions answered anonymously because they are not as adept at using electronic devices as the younger generation and are scared of using the internet.

She also declared that magazines can still be used to make bold statements and to provoke important conversations. She provided an example of a recent controversy with a magazine regional to Kerala, where the cover page boldly modelled a breastfeeding mother. She explained how one simple, bold representation of breastfeeding mothers provoked a reaction among the masses and ignited a must-have conversation about normalizing breasts.

“I say go for the extreme. It’ll be difficult, but so worth it. Say, the Malayalam magazine that featured the breastfeeding mother. That itself brought along so much conversations about the symbolism of breasts.”

She finally reiterated the significance of magazines in providing diagrammatic and visual aids that teach many women how to self-examine their breasts.

The lack of responses about print media surely points to the obsolescence of magazines and newspapers, but there is still evidence that bold statements and visual aids in print media can support the process of enlightening the masses about BC screening.

### ***Message Tone: Fear***

Fear has been a popular motivator used in messaging, especially for preventive health communications. Participants expressed their views and opinions about using fear appeals in BC related messaging, however, the opinions were quite mixed.

Participant (6) expressed her strong opinion that in matters of health, fear needs to be induced in the audience. She stated that fear of consequences can lead to major behavioral changes. She elaborated,

“So yeah, kind of, I would say a little fear sometimes. Hmm. So, uh, something on that note, like, you know, some, some, uh, stories about people who have recovered, but then what all they went through, those are even those who recovered.

I'm sure they would have gone through a lot from the time they got diagnosed. And then, uh, they got treated. So what they went through could have been avoided, had the diagnosis happened a little earlier, some message on that one, those lines, but it does communicate. I mean, that's how I want you to start with and then come to the part about how to do the self-examination. Then I think it would hit the point, right. In the sense that first, there's no need to get down to a, a very bad or a worse situation when there is something that you could do to avoid that. Hmm. Ads should include two things for me, a woman should respect her body and health and the consequences if not detected on time. There should be a little fear.”

Participant (8) also believed that fear is an important element of messaging for BC screening. She stated,

“Health is live or die. It is hard to change if you don't fear the die part.”

Other participants, however, were wary about using fear as a messaging element. Participant (1) stated that using fear psychosis can backfire if not used correctly. She explained that BC is a sensitive topic to create messages on, and if fear appeals are not used properly, it could lead to people avoiding the message altogether, which is an undesirable outcome. She stated,

“In the smoking non-smoking ads, they use a lot of fear psychosis, which is very evident, but in this, this is more of like a, you should do this, you should do that. And this is what

you need to do. Like it's just informative more than, and I doing using fear psychosis here would be like, have a bigger impact. But then again, it's an issue that cannot, that has to be taken up sensitively, I think. So yeah, fear psychosis have, you know, they work up till a certain point. Like if. You, it will just lead people to just avoid the ad than anything. Yeah. Life insurance uses fear psychosis, but I don't know if that same appeal would work here. Yeah. It needs to probably take a different thing.”

She shed light on how fear appeals might not always be the best approach for influencing preventive health behavior. Participant (11) also stated that fear of the disease has always existed and won't make much of a difference in influencing people for BC screening.

While people's opinions about fear appeals were few, the available data informs us that the use of fear in a sensitive matter like BC can easily go wrong. If being used, fear must be dealt with systematically and only after substantial testing.

### *Message Tone: Educational*

Participants expressed that they would prefer to be educated through messages. Owing to their general lack of awareness about breast health, participants claimed that it would be more effective if educational messages were aimed to spread BC awareness. Participant (1), after rejecting the use of fear psychosis in messaging, claimed that BC messages would be more effective if they were calm but firm, and informative.

Participant (11) also stated the same, by explaining,

“No no, fear is already there. It is secondary. Awareness is more important.”

Based on the interviews, the belief was that informative messaging would shed light on the seriousness of the disease that would automatically induce a fear of consequences.

Participant (12) had a slightly different take on informative messaging, however. She stated that the audience needs to feel “stupid” about not knowing enough about BC and screening. She stated,

“We should start with breast health particularly, but it has to be in a very, very, the tonality has to be, I think, little bit more smarter in a way that you're, you're indirectly telling the person that you're stupid. If you don't know your own breast health, and if you are not acknowledging it. So the connotation or the tonality has to be in such a manner. Like it makes you wonder that am I stupid to not think or talk about it? So that is when it hits you. And that is when you take an action of order.”

The general lack of awareness portrayed across the interviews, as discussed in the beginning of this chapter, suggests a strong educational tone be employed. Participant (4) advocated for an educational tone that proposed information of how to conduct BSE along with an iteration of the importance of screening. She stated that an informative approach in teaching the audience the method would be more effective than just communicating the significance of regular screening. Participants agreed that visual representation of the method would be most effective and would also be an element they could rely on and revisit, allowing them to regularly self-examine. Participant (1) supported this argument while rejecting fear appeals. She emphasized that BC requires a sensitive approach that should involve education and awareness, as it requires the audience to be aware of the importance of screening and at the same time, learn a lifesaving behavior. She stated,

“I think, um, the appeal should be more of like a caring point of view and more of an informative and aware point of view.”

### *Message Content: Propagating Awareness*

As discussed throughout this study, there is an overall lack of awareness among the participants. Over the interviews, participants expressed their confusion and lack of understanding of the disease altogether with rigorous candor. It was observed that participants' knowledge of the disease was limited to generic cancer knowledge—the trauma following diagnosis, chemotherapy, possible mastectomy, and loss of hair. Participants were unaware of risk factors and, as was observed under perceived threat, unaware of genetic factors that put women at a higher risk.

Participant (1) expressed her frustration at knowing very little about BC and screening. She stated that “something needs to be done.” Her frustration could be attributed to the various factors discussed in perceived barriers that contributed to her being forced to stay in the dark about the disease. She stated,

“I have zero information on this (screening methods). I was never educated about this.”

She further stated that things need to change and awareness needs to take priority. She stated,

“People in the school, which I think should be important, people, children who are children as in school, going adolescents who are 15, 16, umm 14 to 16 years of age, should be aware about this. They should be made aware, however uncomfortable they are. They should be made aware about this, for sure. Yes. If not, then, then if not that then definitely, uh, students who are in their bachelors or PG, that's still, there's still an opportunity there because, because there's such a large number of women in India who are not aware about this.”

Participant (2) shared this frustration by speaking about how she was never aware of the importance of prioritizing her breast health until she had a personal scare. She explained that her lack of awareness led to her forgetting to screen herself regularly, and that she wasn't jolted out of this till she noticed a lump on her breast. It was only then that she openly educated her daughters about BSE and made sure they screened themselves regularly. She iterated that awareness was an important part of taking the first step toward prioritizing breast health.

Participants also expressed that they only understood the importance of BC screening through the course of their respective interviews. Participant (4) voiced this frustration by stating that she would have committed to regular screening much earlier if she knew early detection was the key to beating BC. Stating her preference of receiving any and all information about her health and body, she stated,

"I need information. I find it helpful to know that early detection is important if I get breast cancer."

Participants advocated for educational tone in messaging, keeping in mind that they needed to be made aware of the dangers of BC and the importance of regular screening. Participant (3) declared that the onus of screening lies with the individual, but if they are not aware of anything related to the disease in the first place, that onus is also taken away.

Participant (5) and (13) were well-informed and advocated for their breast health to their respective doctors, and claimed the only reason they were able to do so was because they had taken up the responsibility of educating themselves. They both participate in regular screening (mammograms) and even included it in their health and wellness plans.

Participant (11) stated that while she wasn't afraid of BC, she would still have liked to be kept informed. However, she mentioned that awareness wouldn't guarantee action.

Participant (12) stated that her lack of awareness stemmed from society's general avoidance of the topic. Giving an example of polio from a few decades ago, she stated that an intensive messaging was needed to ensure everyone was able to talk about it. She supported her opinion by saying that messaging needs to focus on the significance of early detection. Stating that the cause would be lost if people are unaware of why early detection is important, she elaborated,

“Uh, and that is where, uh, and every ad or every corner has been speaking it loud and clear that you need, you need an early detection, but if you don't get yourself a scan, early detection won't happen. So it needs to get ingrained, like how polio has become a de facto for every child. This should also become a defacto for every 30 plus woman, whatever is the age bracket. So it needs to go that deep. And I think, uh, polio became that deep because we had a lot of cases pre 1980s, 1990s, uh, pre 1980s, actually. And, and the government of India took the initiative. They started doing it and they started, uh, putting it out and they took the right people to endorse it. That is something that really worked really. I mean, the budget was there and every house, or every medium, the public service announcement was there everywhere across. And it was a year long thing and they had made it up, I think, they made it free when you can get three doses, something like that. So that is a fantastic way in which they pushed it, but of course, uh, uh, polio is a different deal altogether compared to cancer.”



Participant (15), an army doctor, sadly explained that she saw many cases of breast cancer where the women were unaware of even the symptoms. She strongly advocated for an entire course on understanding breast cancer for the masses to make sure no one misses the symptoms. She stated,

“Everyone knows when they have a fever, when their blood pressure is fluctuating, but no one tries to know about their breasts. They come in so late after they have gotten more serious symptoms. They have breasts, they should know what’s normal and not normal all the time.”

Participant (13) also suggested adding breast health as a part of sex education by giving her opinion that the generic sex education modules are based mostly on “cis-het” male bodies, meaning that the modules were largely centered around cisgendered and heterosexual physiologies.

The researcher observed a series of emotions revolving around the participants’ lack of awareness throughout the interviews, bringing to focus that messaging interventions need to be designed to spread awareness about BC, including risk factors, symptoms, and screening methods. Spreading awareness would be the first step to influencing overall engagement in regular BC screening.

### *Message Content: Communicating Responsibility*

The interviews revealed that participants preferred communication efforts focused on enlightening the audience about responsibility. Mass communication, while appreciated as a useful source of information, wasn’t enough for ensuring behavioral change. Participant testimonies revealed that there need to be more efforts outside of mass communications, and that

they preferred to receive their information from sources they trusted, namely people who they had a personal relation to or someone they relied on for their expertise. Their preference for interpersonal communications in combination with mass communications was evident across their testimonies.

For instance, participant (1) expressed that her mother would probably prefer to be educated by her peer circles. She explained that her mother's generation was keen on maintaining their relationships and often shared personal experiences and advice. Believing that her mother would trust information from her friends over mass communications, she stated,

"I think just making this conversation, um, something that is more comfortable in their (peer) circle, will bring that awareness within them. So maybe encouraging all of them as a group to participate in a certain activity of say painting and through that painting class, they are then discussing more about these, these topics and these issues. And then they're further and going to the other circles and spreading that knowledge."

Participant (3) supported this perspective by explaining further that peer groups allowed for friends and family to check in with each other. She considered this to be an important addition to mass communication efforts. She explained,

"So I think, I think the next generation is a lot more open, uh, but the older generation, what we could do is talk about it more or checking on each other as simple as, Hey, did you get it done on, um, you know, not as a cause of alarm, but as a cause of like, just checking in the way you check in on how you feeling today, check in on each other like family. Hey, you know, when was the last time he said it's examined that kind of thing. So that will be one way of doing it. So it's, it's an informal casual way."

Participants wished for a multi-level approach that involved both mass communications and interpersonal communications. They believed that the former had great power to influence the latter. Participants were probed further to reveal two sub-themes: Communicating responsibility to mothers and communicating responsibility to medical practitioners. In addition to being able to hold the audience accountable for their health actions, participants felt that mass communications designed with these content themes in mind had great chances at influencing a behavior change.

#### *Communicating Responsibility: Mothers*

Participants expressed that they felt most comfortable being advised about their breast health by their mothers. Sociocultural barriers have played a significant role in denying Indian women the opportunity to communicate their queries and concerns about their reproductive health with their mothers.

Participant (1) stated that her mother never prioritized her own health, and it was impossible and uncomfortable to have an open discussion about her reproductive health at home on account of avoiding unnecessary questions and remarks. She stated,

“Uhh my mother never cared for her health. I remember, she used to care for us when we were sick but if she’s sick, she’s still worried about who will give my father his tea and all.”

Participant (4) claimed that she would find her mother to be the most credible source of information. She explained that she trusted her mother to provide her with information that would prove to be beneficial to her well-being. However, she did address that family and cultural

dynamics played a role that resulted in her not receiving the information from her mother. She stated,

“I want to be able to talk this out with my mother. If it’s (breast cancer) so important, it’s better if I navigate through it with my mother... If the ads told my mother to discuss with me, it would be great.”

She went on to suggest interventions focused on family’s significance in propagating positive attitudes toward breast health.

Participant (2), a mother herself, stated that she was comfortable with her daughters receiving information from her, and went on to explain that it would be helpful if messages targeted mothers to open up to their daughters and discuss concerns. She stated that interventions should focus on communicating to both mothers and daughters.

“So, maybe interventions should focus on that, like tell young girls to open up to their mothers... It’ll be mutually beneficial to have that safe place.”

Participant (2) stated further that the internet, while being an excellent platform for gaining information, could also be an unsafe place for young adults. She wanted to be involved in her daughters’ health and direct them to resources accordingly. She stated,

“I prefer that. I mean, to come to me then to go to any other place for information, I mean, some, the net could be a good place. It could be an unsafe place to get, uh, the kind of information you need. So I referred, you know, they come to proper sources, they get their sources. Right. So that they get the information. Right. I'd prefer that than, you know, to get, uh, misinformation.”

Participant (9) also believed that any information about her breast health should come from her mother. She pointed out that her mother had openly told her about her genetic

predisposition to BC and, hence, trusted her mother's judgment. Participant (15) also believed that mothers have a huge role to play in normalizing conversations about breast health, and that their responsibility of the same needs to be communicated through media, especially cinema. She stated,

“See, in a family, a girl will learn only from another female. Who's better than her mother, am I right? If they don't have open conversations, there are so many issues women face and they just have to suffer alone. Now see Bollywood, so many nice mother-daughter stories. If I had a daughter, I would want my daughter to know I am a woman too and I understand. If I don't tell her, where will she know?”

She felt that daughters should be able to approach their mothers for any issues concerning their health without being afraid of rejection, the chances of which are higher in a conservative society like India.

#### *Communicating Responsibility: Medical Practitioners*

Perceived barriers articulated how medical practitioners act as obstacles to accessing BC screening in India. However, participants still believe in the expert opinions of medical practitioners and wished to be communicated to about their risks and any information about BC screening by their doctors.

Participant (4) expressed her confusion over wanting to be able to ask her doctor questions, but consequently worrying about overstepping. However, the interview had her worried about whether her doctor was even invested in her breast health, considering that she had never been advised about BC screening or had a CBE conducted on her.

“I don’t even know if that’s something one should do. I mean, it’s embarrassing to ask a doctor... I guess I’d want to know that it’s okay to ask questions. At the same time, the doctor has to be receptive. I think at this point, I’d feel more comfortable if the doctor themselves told me to ask or told me this is something I should consider... Doctors are supposed to know everything right? So yeah, if breast exam is so important, they should take the first step.”

She further confessed that it would be helpful if doctors were communicated to about advocating breast health to their patients, so as to avoid patients taking the initiative.

Participant (2) also claimed that doctors had to be held responsible for communicating important health-related information to their patients. She admitted that while receiving information from parents was the most ideal for her, it was a difficult reality to achieve in the current society. She stated,

“Uh, you have to find your info on the net. Unfortunately, if you don't have a safe space at home, that is where you need to get the info from. And, uh, I'd say the next time you go to your doctor, you openly talk to your doctor about, uh, the issues that you're facing or the info that you're getting on the net and ask them openly because doctors are the people that you need to talk to ask them openly about the information that you've read and, um, tell them, I mean, they'll clear you, if you have any myths or if you've read something which is wrong on the net, they'll clear it up for you.

I think at least if not at home, you should at least be, um, open to talk to your doctors. Even if it's a family doc, even if it's a normal, uh, family, uh, primary health care provider or your family doctor, as we say in India, even those guys, they might not be super

specialized. Even those guys can, you know, put you on the right path. Yes. They'll give you the correct information."

In addition to communicating awareness to patients, she believed messages need to be designed to avoid patients taking the extra mile to advocate for their own health.

Participant (7) also expressed her ambiguity by stating that she did not want to go and manifest a disease on herself by just starting a conversation with her doctor and would rather prefer that the doctor inform her themselves. She stated,

"Oh, I think until the doctor tells me, doctor educates me, so I would feel that would be a very credible source for me, rather than reading it around on the internet or having mails or having, uh, ad messages. Rather than that, if the doctor tells me whenever I go to a doctor for anything, like if I'm accompanying a relative, my family member for checkups or I'm going for my own checkup. So if the doctor says, then, then probably I would take it more seriously personally."

Indians, even with their subscription to alternate medicine, wholeheartedly believed in their doctors, and patient advocacy was an alien term to most of them. Participants trusted their doctors entirely and believed that any form of communication about their breast health would be the most credible coming from them, and hence pressed for messaging content on communicating responsibility to the doctors themselves.

## **Chapter Five: Discussion**

The following chapter will detail the findings of the study to answer the questions framed in the second chapter. The chapter will also elaborate on how the individual themes relate to designing messaging interventions. Breast cancer is reportedly the most fatal cancer in India, despite the fact that only half of the country's population is at risk. Due to the sensitive nature of the disease, accounting to the fact that it affects a conservative body part, BC is a largely undiscussed topic and is often diagnosed very late. Late diagnosis of BC stems from patients' general lack of awareness about breast health and the medical practitioners' lack of initiative in educating patients. Lack of awareness in patients results in not having regular gynecologist appointments, not being able to advocate for a body part that is inherently feminine, and in many cases, death that could have been avoided. This fact alone makes creating interventions to inform the public about BC a priority.

This study fills an important gap in the literature since Indian scholars have only recently begun understanding the criticality of the BC epidemic (Sullivan et al., 2014). It is widely accepted that BC mortality rates are at an all-time high in India, which is a consequence of late or non-existent diagnoses (Agarwal & Ramakant, 2008; Sathwara, Balasubramaniam, Bobdey, Jain, & Saoba, 2017). Medical scholars have conveyed the significance of this issue, as late diagnoses have an undeniable effect on the long-term prognosis and quality of life of BC patients, especially regarding how to manage this problem.



Indian studies fall short at medical recommendations and suggest directed efforts at increasing awareness (Gadgil et al., 2012; Mitra, 2008; Sathwara et al., 2017). Despite these recommendations, there are no studies that have objectively investigated levels of awareness, as is the case in many Asian countries (Solikhah, Promthet, & Hurst, 2019). There is limited knowledge about what brought on these low levels of awareness. This study attempts to consider that lack of awareness in relation to Indian women's health beliefs.

The study adopts a qualitative approach to gain a deeper understanding of how one's lack of awareness affects health beliefs, thereby affecting their health behaviors. Moreover, the study attempts to provide a guideline for health communicators in India by shedding light on the health beliefs that have emerged because of unawareness. This knowledge is of utmost importance for communicators to design interventions for influencing behaviors. To the knowledge of the researcher, this study is the first of its kind, in the sense that it adopted a socio-cognitive route to inform the designing of mass communications. It is pertinent that Indian health communicators consider an iterative approach to propagating BC awareness, and this study, with its consideration of health beliefs, is a first step in achieving that goal.

The study employed the Health Belief Model for the purpose of achieving an iterative approach to creating mass communications. For mass communications to truly influence health behavior, it is important to rely on and have an open communication about the audience's opinions and beliefs (Cassell, Jackson, & Chevront, 1998). It is only then that the audience can be persuaded into a behavior that is alien to them. Moreover, health communications, especially in the form of mass communications, rely on "social influence" or external influence (O'Keefe, 1990), but they are only effective if the audience is also influenced internally. This means that the

audience's internal attitudes and opinions have a significant role in their response to external influence. HBM assists this study by helping assess these attitudes that inform their health beliefs. These health beliefs are defined with the framework's constructs.

Themes emerged relating to the constructs of HBM, which, in turn, proved helpful for creating mass media interventions. Many participants reported their lack of overall awareness about BC, claiming their awareness to be isolated to generic cancer. HBM acts as a useful framework for understanding the psyche of Indian women in the context of BC and provides useful information for future research. The following research questions were developed by the researcher, alongside HBM constructs, for aiding the pursuit of understanding the messaging needs of Indian women.

#### **Answering RQ1: Perceived Threat**

Champion (1987) stated in her revolutionary studies that people need to feel threatened by a health issue to effectively invest in changing their behaviors. As per the HBM, people's perceived vulnerability to a disease can be defined as perceived susceptibility. At the same time, people need to believe in the disease sincerely to truly feel the effects of contracting the disease. This can be defined as their perceived severity. Perceived susceptibility and severity together define how people perceive the entirety of the disease, and people invest in behavior changes only when they're threatened by it. As mentioned earlier in the second chapter, perceived susceptibility and severity are constantly influenced by each other and moderated by a third reliable construct, that is, perceived threat. Perceived threat is the weakest predictor of health behavior change compared to other HBM constructs (Tanner-Smith & Brown, 2010). However,

this construct addressed the initial responses of the participants and shed light on how Indian women are unaware of the risk of BC, and how this affects their health beliefs.

The interview results revealed that most of the women did not feel particularly threatened by breast cancer. In fact, they were rather immune to the knowledge of the severity of the disease. While some acknowledged their genetic predisposition to breast cancer, there was still heavy denial that the cancer would affect them. That is, despite knowing the reality of the disease, the participants held a strong opinion that there was no way they could be affected. This severe denial could just be optimistic bias, or in other words, unrealistic optimism (Weinstein, 1989), which is a phenomenon where individuals believe they are immune to negative outcomes (Weinstein, 1982). This exists either as a comparison to the rest of the society (McKenna, 1993) or remains isolated to just the individual (Perloff & Fetzner, 1986; Williams & Clarke, 1997). Optimistic bias can stem from different emotions or life experiences, but ultimately, it means that the individual sincerely believes they are invulnerable, which in turn, creates a nonchalant attitude.

Optimistic bias creates a major challenge to mass communicators, in that, the priority becomes addressing their unrealistic optimism first. This becomes a significant first step in addressing the BC epidemic in India because the very phenomenon of optimistic bias drives their health beliefs about the disease as well as its preventive measures, which in this case are screening methods. However, this phenomenon provides an implementable direction, that mass communications need to focus on redirecting the audience to properly consider the risk and seriousness of BC.

Additionally, participants were genuinely fearful of the trauma that follows cancer. Again, this perspective was not isolated to breast cancer, but was for cancers in all shapes and

forms. In the context of BC, participants were found to be specifically wary of the cancer consequences of mastectomy and hair loss, which they admitted they considered to be a symbol of their femininity. Additionally, they were also worried about how a possible cancer diagnosis would impact their mental health and professional career.

It can be inferred that while there was an air of nonchalance toward the reality of being affected by breast cancer, participants did seem to take the disease seriously when they personally knew someone who was battling or had battled some form of cancer. Personal scares were a motivator for taking the disease seriously. Moreover, the participants also admitted that this personal effect of breast cancer could warrant a behavior change in them indefinitely.

The findings on perceived threat from this study are congruent with the past literature. Roche et al. (1998) reported that women often have a different understanding of medical terms in comparison to medical experts, and this often skews their understanding of BC related messages. The interviews revealed that the participants required more context to answer questions related to risk factors. The answers were isolated to their own understanding of cancer and what they vaguely remember from random exposure to information.

Participants also believed it was highly unlikely that they were at risk for breast cancer. Scholars (Absetz, Aro, Rehnberg, & Sutton, 2000; Aiken, Fenaughty, West, Johnson, & Lockett, 1995) claim that women believe in unlikely odds either because they are comparing their odds with other women that they consider to be at higher risk or because they believe their individual odds are positive. This can lead to two scenarios: overestimation of risk or underestimation of risk. This study's findings reveal that Indian women are dangerously underestimating their risk

of BC, especially in cases of existent genetic history, and this provides a second direction to mass communicators that there is an underlying third-person effect (Davison, 1983) at play here.

Third-person effect in communications is a phenomenon where people perceive messaging to be highly impactful for others but not themselves (Davison, 1983). As discussed earlier, participants in this study exhibited a high degree of nonchalance about BC, which as one will observe in consecutive findings, affected their approach to screening and preventive measures. This nonchalant attitude, along with their optimistic bias, has a significant hold on the Indian audience which impairs their ability to truly act on the BC risk.

Personal nonchalance or low personal perceived threat (or risk) of a disease can result in the audience omitting important details of a message even when exposed to mass communications (Liu & Lo, 2014). This results in the audience only focusing on the disease itself, albeit in a detached and unaffected way (Trope, Liberman, & Wakslak, 2007). This proves to be a challenge to mass communicators but does provide an important direction, that mass communications need to focus less on the disease and more on the screening. Scholars suggest that in a health scenario with extensive third-person effect, the audience tends to respond better to the epidemic at hand if they're provided with a solution or a prevention (Liu & Lo, 2014). An integrated approach with the objective of tackling the audience's optimistic bias and catering to the Indian audience's third-person effect by providing screening solutions would be the most recommended approach. This means that mass communications should be designed to make the audience realize the threat of BC and simultaneously provide screening information that will help them tackle the threat.

Perceived threat toward reproductive diseases like cervical cancer and breast cancer has always been low for women (Curry & Emmons, 1994). However, scholars have always considered women's perception of real risk and family history of breast cancer to predict screening behaviors (Stein, Fox, Murata, & Morisky, 1992; Drossaert, Boer, & Seydel, 1996). Congruent to the study's findings, the knowledge of direct risk of the cancer and how the disease can affect their mental health and family has been an important result (Aiken, West, Woodward, & Reno, 1994).

Cues to action, as informed by the HBM construct of perceived threat, communicate the reality of the disease. In the case of this study, the optimistic bias and the third person effect indicate a severe low level of perceived threat. Past studies have suggested that perceived threat, while a significant construct of HBM, has been the weakest predictor of health behavior, which is evident in this study as well. However, there is some crucial significance to this result, in that it informs mass communicators the initial challenges that need to be overcome (optimistic bias and third-person effect) in order to effectively motivate the audience to engage in BC screening behaviors.

The objective of this study is to elaborate on how findings in the context of HBM constructs can inform the creation of messaging interventions. As mentioned previously, women are uninformed about the jargon surrounding BC. Moreover, there is gross underestimation of their risk, either because of optimistic bias or because of lack of awareness. On the other hand, there is a genuine fear of cancer fueled by personal experiences and scares. These findings can be used to create effective mass communications as they provide a deep understanding of how Indian women perceive BC as a threat, which in turn informs how they perceive language and

content surrounding risk-related messaging (Katapodi, Lee, Facione, & Dodd, 2004). However, there is a need to understand health beliefs surrounding screening measures.

### **Answering RQ2(a): Perceived Benefits**

Women's participation in BC screening is a personal choice which requires conscious understanding of what the procedure entails. In order to make an informed decision about partaking in BC screening services, it is important to have an understanding of what benefits are involved. This particular research question tries to find out what benefits Indian women perceive in their pursuit of BC screening. It does so to inform what benefits have remained forgotten or uninformed, which can be incorporated into communication interventions.

Participants reportedly considered BSE to be the most preferred method of screening because of the convenience of accessing it without the use of any resources. Additionally, the participants even mentioned that they found an emotional benefit to engaging in breast cancer screening, in terms of feeling empowered. Here, it is important to note that the participants were hardly engaging in regular breast cancer screening and were speaking in terms of "wanting to feel empowered". They believed that breast cancer screening was a way to gain control over their bodies and themselves. It was also a way to gain information about themselves, and they found this clause to be powerful to them. In fact, they claimed that breast cancer screening would allow them to be empowered by information about their intimate selves, and they found this to be highly beneficial.

Despite being cognizant of the ease of engaging in BSE and wishing to feel empowered through BC screening, most participants were not regularly engaging in any kind of screening.

This means that knowledge of benefits does not necessarily guarantee an uptake in BC screening (Hersch, et al., 2015).

It is also interesting to note the scarcity of findings for perceived benefits. Whether this is because of lack of knowledge or because of lack of initiative by the participants can be further explored in future studies. However, the scarcity does point to communicators to better propagate the benefits of engaging in BC screening. Perceived benefits form an important aspect of public health communications, especially when communicated in collaboration with perceived threat.

#### **Answering RQ2(b): Perceived Barriers**

The interviews and analyses revealed that perceived barriers were the most indispensable results. Primarily, the results suggested that India's progress into propagating breast cancer awareness has been dangerously slow. In fact, there is a lack of awareness in almost every aspect of understanding the disease.

It was also observed that there are many systemic forces that act as barriers to engaging in breast cancer, cultural factors and the nature of the Indian healthcare system being the most apparent ones.

The Indian healthcare system has been found to be strictly responsive in nature and hence, has hardly entertained precautionary measures. The participants reported that their healthcare practitioners never informed them of the importance of breast cancer screening and, more importantly, never conducted CBE on their patients. In fact, conversations with the participants revealed that any information of BSE was provided only if the patients asked. Even mammograms and CBE were performed only on-demand. This means that healthcare



practitioners expected their patients to advocate for themselves, which proves to be a challenge with the widespread lack of awareness.

Moreover, the lack of awareness and hesitance to have a dialogue about breast health is deeply rooted in the patriarchal nature of Indian society and also the cultural dynamics of how women are supposed to conduct themselves within their families. Younger participants even admitted that they may have inherited their mothers' hesitance to be comfortable with breast health, hence avoiding the topic altogether.

The perceived barrier results also emphasized how interwoven the components of HBM are, that is, it can be seen how the barriers behave as the root causes for a multitude of perceptions that each behave as a barrier unto itself. For example, the patriarchal society affects people's level of awareness about breast health, which in turn, may affect how they perceive any breast cancer-related information they come across. In fact, they may be reserved and unaware to a point where they may feel uncomfortable even being exposed to such information, which would lead to a deeper level of unawareness. On the other hand, culturally charged beliefs like karma would push them deeper into denial and refusal to accept the seriousness of the disease or their vulnerability to it. In other words, culturally driven beliefs feed the participants' optimistic bias.

Finally, perceived barriers also shone a light on Indians' affinity toward alternative medicine like homeopathy that avoids precautionary medicine. It was also found that there is a general distrust of "western medicine" altogether that has limited people's interactions with medical practitioners. Women don't consult a gynecologist unless they are pregnant or have a UTI. They may also be avoiding the doctors in fear of what society might think, but ultimately,

the lack of interaction with gynecologists limits their exposure to breast health-related information.

The findings around sociocultural barriers are congruent with the literature. A recent study in India reported that Indian women's socioeconomic status affects their access to BC screening (Patil, et al., 2022). Past studies have also shown that patriarchal culture forces women to prioritize their duties as mother, wife, and daughter, over their own health. Here, the barriers are not just isolated to BC, but to the overall health of women. Studies point to the need of addressing socioeconomic gaps to increase women's health literacy in order for women to have autonomy over their reproductive health decisions (Gupta, Shridhar, & Dhillon, 2015). It has also been found that Indian women are unaware of BC and screening procedures despite their socioeconomic status (Patil, et al., 2022), which is clearly the case in this study.

With such socioeconomic and cultural barriers creating obstacles for women in their pursuit of BC screening services, there's an urgent need to prioritize eliminating the barriers through public health communications and interventions.

### **Answering RQ3: Mass Communication Elements**

The goal of this study has been to inform cues to action in the context of breast cancer screening to influence early detection. There has been little-to-no research on cues to action (Carpenter, 2010) and this paper attempts to take a step in the right direction, which is implementing informed interventions. In fact, HBM-based interventions were found to be highly effective and relevant in a culturally complex region like Iran (Torbaghan, Farmanfarma, Moghaddam, & Zarei, 2014).

Hochbaum (1958) had stated that perceived susceptibility and benefits were the most relevant only when initiated by well-designed cues to action. However, Stretcher and Rosenstock (1997) added to this by saying cues to action are even more effective when they are implemented through perceived threat.

Findings from the study suggest that participants are most enthusiastic about being informed about BC and screening through cinema and social media. However, a few participants admitted that print media, in the likes of newspapers and magazines, was their first source of information about the disease.

India hosts the world's largest population of youth and as of the year 2022, over 859 million people use smartphones daily. With WhatsApp and Instagram being the most popular social networking site, social media has a wide reach in propagating health education in India with over 400 million users. Social media allows for high quality content with cost-effective ways to communicate to the audience using professional quality photographs and videos. Moreover, it provides communicators with an interactive and visual medium to effectively communicate information that can be immediately accessed by the audience.

Social media is growing to be the most trusted source of information about cancer. With an increase in the number of influencers, especially sex education specialists and new mommy bloggers (Miller, Guidry, & Fuemmeler, 2019), social media provides the audience with authentic and credible information about their bodies. Indian women are relying on social media on a daily basis for health education, including information about lactation/breastfeeding and various reproductive cancers, and believe in Instagram influencers for obtaining credible information (Subburaman, Parangimalai, Iyer, & Sukumaran, 2021). Additionally, social networking allows

for a constant exchange of information among peers and friends, thereby initiating a virtual word-of-mouth exchange of information (Garven, 2010). It is a strong recommendation for health educators in India to utilize the popularity of social media to propagate the importance of early detection and BC screening.

Participants revealed that interpersonal communication between themselves and their provider was of utmost importance to them. Healthcare providers must be considered to be important stakeholders or audience for mass communications as they are preferred sources of BC health information for their patients (Greenfield, Kaplan, & Ware, 1985). This is an important consideration as healthy patient-provider relationships ensure compliance and confidence in patients to engage in screening behaviors. Moreover, healthy relationships with doctors encourages an open and safe atmosphere for queries and questions. Mass communication efforts must be directed to encourage a culturally positive dialogue to tackle the severe hesitance that Indian women have toward screening (Kreps & Kunimoto, 1994).

Family members, especially mothers in the case of BC, are primary sources of health information in a developing country like India (Kreps, 1990; Kreps & Sivaram, 2008). Culturally, Indians are in collectivistic group dynamics with their family members and look up to their parents for any important health information (Kreps, 1990). Strategic mass communications should be directed at educating family members to educate the children and young adults about early detection, risk factors, and screening methods (Kreps & Sivaram, 2008). With social media and cinema being popular mass media channels, content can be curated toward mothers to advocate for their children's health by initiating health education themselves (Kreps & Sivaram, 2008).

The final research question highlights the use of various message tones for effectively influencing early detection behaviors in Indian women. Participants, while unable to comment on their own response to fear-based messages, believed that fear was a great motivator for Indian women. Participant (8), suggesting that “health is live or die”, suggests that women need to truly fear the disease to effectively make efforts to employ healthy behaviors. However, a few other participants communicated their reservations about using fear as a motivator, and believed educational and empowering tones would have more positive effects.

The research question also attempted to highlight themes of messaging content that would be effective in influencing screening behaviors. Participants wanted to be informed about their health and their bodies at all times. Through the course of the interviews itself, participants were in the process of enlightening themselves and claimed that they would have engaged in BC screening beforehand if they had known about the benefits of engaging in screening. They wished to be informed about the importance of early detection of BC even if they weren’t at risk, genetically. They also wished to be more informed about precautionary measures that weren’t generic in nature. By this, they meant that they were aware of general health precautions to take but were in the dark about direct approaches to BC prevention. Finally, participants wished to receive their information from people they trusted. Participants who were mothers wished to be the bearers of information for their children, and wanted to be communicated to about their responsibility as a woman and mother. Younger participants also wished for their mothers to be communicated to about the importance of propagating breast health to children, as they trusted their mothers the most.

A thorough analysis revealed that participants expected more than mass media messaging. They wished to be better equipped with knowledge through sex education and believed acceptance and normalization of breasts was the first step to that. Moreover, they wished to be able to receive information about breast health from their medical practitioners. They preferred to have an expert educating them instead of the media, and they wished to gain information without having to advocate for it or without overstepping with their doctors. Finally, younger participants believed that peer circles were important for their mothers to be educated about breast health.

The findings suggest that a multidisciplinary approach is needed in communicating to Indian women. Patil, et al. (2022) reported findings that, along with messaging campaigns focused on increasing breast health, literacy, awareness, and screening camps were a significant addition to influencing positive action. It is of the researcher's opinion that combining efforts to tackle all health beliefs barricading regular preventive measures are highly needed.

Moreover, an abundance of literature submits that while HBM is a well-designed framework for designing effective interventions, the framework is still criticized for being able to tackle only one perception at a time. Keeping this critique in mind, it is highly recommended to adopt an integrative approach to designing interventions (Champion & Skinner, 2008). Specifically, cues to action should be designed to increase perceived threat and benefits, and simultaneously eliminate perceived barriers.

## **Limitations**

A limitation of the present study is the availability of one coder. Having a second coder would have helped increase the reliability of the data. Another limitation of the study is the narrow selection of participants in the context of socioeconomic status. Having a diverse population from varied backgrounds would have allowed for many new themes to emerge. India is a land of many cultures and religions, and having a varied population would have brought forth more detail into how sociocultural factors affect access to BC screening. Finally, more training on the researcher's part is needed to probe more descriptive answers from participants. Despite the limitations present in the study, it has several strengths. In being the first study of its kind, this paper provides direction to future researchers to approach mass communications in a systematically academic and practical way.

## **Directions for Future Research**

In conducting future studies, it would be beneficial to use the findings from the present study to create messages for testing. Testing the messages would provide more insight into people's opinions about the content and tone of messaging. A quantitative research into studying traffic and response to tailored social media messages would also help in understanding the efficacy of such messages. Finally, an in-depth study of how Indian cinema is used as a tool to tackle social issues to inform future movies about BC would also be beneficial. Creating mock-ups of content for testing will provide deeper insight into the audience's responsiveness to the messages.

## Conclusion

This study expressed how Indian women perceive breast cancer and screening to inform the creation of messaging targeted to increase the uptake of screening behaviors. The researcher made recommendations, based on findings grounded in the Health Belief Model, that are believed to be most effective in influencing behavior change.

The findings of perceived threat informed that Indian women aren't concerned about their risk of breast cancer, despite having genetic predisposition to the disease. It shed light on how, on the other hand, women have a fear associated with cancer that doesn't necessarily affect their perceived threat. However, personal scares and experiences, including loss of a loved one, have a massive effect on one's perception of threat.

The findings from perceived benefits informed that Indian women wish to feel empowered through BC screening and prefer convenience and ease of access to BC screening over anything else. The findings from perceived barriers came to be the most important findings as it shed light on the varied nature of barriers faced by Indian women in their access to BC screening. In addition to personal constraints of age, finances, and time constraints, the healthcare system in India and the sociocultural environment proved to be major barriers in BC screening. These barriers created ambiguity in approaching healthcare professionals about breast health, in addition to the culturally based reservations held by women.

The findings from the HBM constructs provided an insight into the issues that need to be addressed through messaging interventions or cues to action.

The findings from the messaging elements highlighted that cinema and social media were the primary sources of information preferred by Indian women. It also shed a light on how fear-



inducing and educational tones can be used for the benefit of encouraging an uptake in BC screenings. Finally, the findings suggest that messaging interventions should include information about the importance of early detection and what comprises as precautionary measures in the context of BC, in addition to encouraging mothers to share breast health related information with their children.

This study fills a major gap in Indian breast cancer literature in the sense that it provides a baseline for the next steps to be taken in designing interventions for influencing healthy BC screening behaviors. The study employs HBM for qualitative research uniquely to inform messaging. In using HBM, the study goes beyond just gauging levels of perception; it tries to describe reasoning and emotions associated with the perceptions. With India's lacking research on solutions to tackle the rising BC mortality rates, this study fills in the gap by suggesting messaging elements for influencing early detection behaviors. Many more steps are needed in the direction of achieving seamless communication about BC in India, including testing message content, but gaining information about existent notions about the disease and screening methods is a noteworthy first step in the direction.

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## Appendix A: IRB Document



### EXEMPT DETERMINATION

August 10, 2021 \* This letter supersedes the previous letter dated August 9, 2021.

Srisai Kamakshi Ramya Harika Pucha



Dear Srisai Kamakshi Ramya Harika Pucha:

On 8/7/2021, the IRB reviewed and approved the following protocol:

Application Type:	Initial Study
IRB ID:	STUDY003085
Review Type:	Exempt 3
Title:	Communicating Breast Awareness: Using the Health Belief Model to develop messaging themes for influencing early detection behaviors
Protocol:	• IRBProtocol_CommunicatingBreastAwareness;

The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BullsIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

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#### Institutional Review Boards / Research Integrity & Compliance

FWA No. 00001669

University of South Florida / 3702 Spectrum Blvd., Suite 165 / Tampa, FL 33612 / 813-974-5638

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## Appendix B: Interview Guide

Hey/Namaste! How are you doing? Thank you so much for agreeing to meet with me today! I have us scheduled for an hour together. Does that still work for you? I want to honor our time constraints. So, while I encourage you to elaborate on your answers to my questions, there may be times when I redirect, so that we may be sure to cover all our bases within the hour.

My name is Ramya, my pronouns are she/her/hers and I am a graduate student at University of South Florida, Tampa FL. I'm conducting these interviews for my masters thesis.

You are participant \_\_ and that's how your information and interview will be saved. For the purposes of maintaining your confidentiality, I shall refer to you by this pseudonym of your choosing or I can call you " \_\_".

Your participation is entirely voluntary, and if you are not comfortable with a question, you may choose not to answer it. Just say, "I'm not comfortable answering that question". There are no right or wrong answers. All comments, both positive and negative, are welcome. I would also like to record this interview so we make sure that we do not miss anything and can write it down later. When I transcribe this interview, I will not write down your personal information so there will be no way to identify what you have said after the contents of the tape have been written into notes. The recordings shall be saved under your given pseudonym in a Google Drive folder and will only be accessed by me and my thesis committee. At any point, you don't understand what I'm asking or if you want me to repeat myself, please feel free to interrupt and ask me to reiterate. At certain points, I may ask you to repeat yourself or confirm your answers just to make sure we're all in the same page.

So, before we begin, I want to start by asking:

1. Can you tell me a little about yourself? (age, sex, pronouns, mother tongue, where are you from, what do you do)
2. What is your relationship/marital status?
3. Are you sexually active?
4. Are you on any birth control? What kind? (trying to establish their comfort of approaching gynecologist)
5. Do you have children? (How many? Their genders?)
6. Do you have/ Have you had breast cancer?
7. Do you have a family history of cancer/breast cancer?
8. Do you have a primary care provider and a preferred gynecologist?
9. How often do you meet with them?

Perfect!

Now, let's move onto some questions about your perceptions towards your chances of getting breast cancer.

Threat:

1. Do you know anyone who's battled breast cancer?
  - If yes, can you describe, to the best of your knowledge, their experience with breast cancer? (testing, diagnosis, treatment, recovery)
  - If not, can you describe what you know about breast cancer? (causes, symptoms, how to protect oneself?)
2. What do you think are the causes of breast cancer?
3. What are your thoughts on a possible/potential breast cancer diagnosis? Describe your feelings about having breast cancer.
4. What, in your opinion, is the lifestyle of women who get breast cancer?
  - How does your lifestyle compare to theirs?
5. When it comes to lowering your risk of a late diagnosis of breast cancer, what do you think can be done?
6. When I say cancer, what comes to your mind? How about breast cancer?
7. What do you know about the symptoms of BC? Describe what you feel about the symptoms. (severity or fear of the symptoms)
8. In your opinion, why is BC termed as the number 1 cancer in India? How do you feel about this particular information?
9. Describe your fear (if any) about receiving a positive diagnosis for breast cancer.
10. How would a breast cancer diagnosis affect your long-term health?
  - How would it affect your family/social life?
  - How would it affect your finances?
  - How would it affect your professional life?
11. Does this fear encourage you or discourage you to get screened?
12. How would your family respond to a positive BC diagnosis? Does your family's fear encourage breast cancer screening?

Next up, can you tell me how your family/friends discuss sex education and breast education?

Benefits and Barriers:

1. Can you describe what you know about the detection of breast cancer?
  - What screening methods are available?
2. What is the most important reason for you to participate/not participate in a screening? What factors do you consider important for partaking in a screening?
3. Which screening method is the most accessible to you?
4. How do you perceive the importance of breast self-examination (BSE) and clinical breast examination (CBE) as a screening method for you?
  - What barriers do you feel going through with BSE and CBE?



5. Have you ever had a CBE? Have you ever scheduled a CBE with your primary care provider or gynecologist?
  - If yes, what influenced your decision?
  - If not, what stops you from scheduling a CBE?
6. Have you ever conducted a BSE? Have you ever approached your provider after a BSE?
  - If yes, what influenced your decision?
  - If not, what stops you from scheduling a CBE?
7. What conflicts do you find yourself facing when seeking breast cancer screening? Describe what you think would override these conflicts?
8. Do you know someone who has performed a BSE?
  - Does an acquaintance with such a person help you perform a BSE yourself?
9. Do you know someone who has had a CBE scheduled?
  - Does an acquaintance with such a person help you schedule a CBE for yourself?
10. Has your doctor or anyone taught you how to conduct a BSE?
  - Does this help you perform one on yourself all on your own?
11. Has your doctor informed you of the importance of breast screening?
  - Does this help you schedule one on yourself all on your own?

Finally, we shall move onto a few questions to know your experience with breast cancer related messages.

Relevant messaging:

1. How do you think you are best reached with information materials about breast cancer and breast cancer screening?
2. Do you watch commercials on TV from start to finish? How do you feel about certain breast cancer awareness campaigns you come across on TV?
3. Are you on social media? Have you come across any breast cancer awareness/screening posts/messages? How do you feel about them and have they helped you make a change?
4. Do you recall any breast cancer screening messages (irrespective of medium)? If yes, what made it memorable for you? Could you please describe the elements/emotions/your understanding of the message?
  - Do the messages scare you?
  - Do they encourage you to consider breast screening?
  - Do you find yourself researching symptoms and causes of BC?
3. From the messages, what screening methods seem to be the most accessible for you? Why?
4. What would you make more likely to understand the message about BC and BC screening?
5. Would you participate in BC screening if your gyne communicated to you about BC screening?
6. Considering your low/high threat to BC, what kind of a message would convince you the best to seriously engage in breast cancer screening?
7. Considering your barriers which are \_\_\_\_\_, how do you see them solved using messages?

8. Do you believe you're in a position to advocate the importance of your breast screening? Who do you believe will make a great spokesperson for people in your demographic?

#### CLOSING

Thank you for being so honest and patient as we talked about these things. I have finished asking all my questions and I want to thank you for participating in my thesis project. Please feel free to reach out to me at [ramyaharika@usf.edu](mailto:ramyaharika@usf.edu) if you have any questions or if you have something else you want to add that you might remember later. Have a nice day!

**Appendix C: Codebook**

<p><u>Perceived Threat</u> The extent to which an individual believes they are at serious risk of BC</p>	<p><b><u>Low Threat</u></b> Participants expressing their low perceived threat of BC</p>	<p>Low Threat: Denying reality of medical history</p>	<p>Participants expressing the existence of family medical history of cancer and/or BC, and the associated feelings of indifference and/or denial</p>
	<p><b><u>High Threat</u></b> Participants expressing their high perceived threat of BC</p>	<p>High Threat: Fear</p>	<p>Participants expressing their fears of cancer, BC, and the various aspects of the diagnosis and the journey</p>
		<p>High Threat: Personal Experiences</p>	<p>Participants sharing their personal experiences with (breast) cancer and their associated perceptions about BC</p>

<p><u>Perceived Benefits</u> The advantages an individual sees in their pursuit of the targeted health behavior</p>	<p><b><u>Ease of access</u></b> Participants declaring the importance of convenience in engaging in BC screening behaviors</p>	<p>Ease of Access</p>	<p>Participants expressing their preference of convenience in the likes of accessibility, location, and time commitment when choosing a BC screening method</p>
	<p><b><u>Feeling empowered</u></b> Participants expressing how they enjoy feeling empowered by engaging in BC screening behaviors</p>	<p>Feeling Empowered</p>	<p>Participants expressing their emotions about feeling empowered through BC screening that pushes them to engage in the behaviors more frequently</p>

<u>Perceived Barriers</u> The obstacles an individual sees or experiences in their pursuit of the targeted health behavior	<u>Personal Constraints</u> Participants expressing the various personal constraints acting as obstacles to engaging in BC screening	Personal Constraints: Age	Participants sharing their reservations about their age in engaging in BC screening
		Personal Constraints: Time commitment	Participants expressing their time constraints associated with engaging in BC screening
		Personal Constraints: Finances	Participants sharing their financial constraints associated with engaging in BC screening
	<u>Healthcare Drawbacks</u> Participants expressing the various roadblocks in the healthcare system that act as obstacles to engaging in BC screening	Healthcare Drawbacks	Participants sharing the healthcare-related obstacles in the likes of nature of the healthcare system, their access to gynecologists, and the doctors' approach to breast health, that have denied them access to information or even BC screening.
	<u>Sociocultural Barriers</u> Participants expressing the various sociocultural obstacles that act as barriers to engaging in BC screening	Sociocultural Barriers	Participants sharing the various family issues, stigma associated with breasts and BC, and the patriarchal family systems that have denied them chances to engage in BC screening

<u>Mass Communication Elements</u> The elements to be considered for designing mass communication interventions for influencing BC screening	<u>Mass Communication Channels</u> Participants expressing their opinions and preferences about receiving information about BC screening through different channels	Mass Communication Channels: Cinema	Participants expressing their strong preference of the use of Indian cinema to propagate the importance of BC screening and destigmatizing breasts for influencing the Indian audience to engage in screening behaviors
		Mass Communication	Participants expressing their convenience and preference of the use of social media for

	Channels: Social Media	normalize talking about breast health
	Mass Communication Channels: Print Media	Participants expressing their opinions about the use of print media for propagating the importance of BC screening
<b><u>Message tone</u></b> Participants expressing their opinions about tone of messaging about BC screening	Message Tone: Fear	Participants expressing their opinions about the use of fear as a motivator in messaging about BC screening
	Message Tone: Educational	Participants expressing their opinions and preferences about using an educational tone as a motivator in messaging about BC screening
<b><u>Message Content</u></b> Participants expressing their opinions on the content of messaging about BC screening	Message Content: Propagating Awareness	Participants expressing their opinion on using mass communications to spread awareness about BC and screening; with an emphasis on importance of early detection
	Message content: Communicating Responsibility	Participants expressing their opinion on including an element of responsibility associated with BC screening in messaging about BC screening; two sub-themes: Mothers and medical practitioners