

# Assessing the Need for Culturally Tailored Care Among South Asian Women with Breast Cancer and Their Caregivers



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Community Partners: Crack the Wellness Code, India Community Center, and the SAFAD Study Community Advisory Board



## BACKGROUND

### BACKGROUND

- South Asian population (Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka) is growing rapidly in the United States.
- Cultural mores are salient in breast cancer e.g., cancer is stigmatized, caregiving roles are gendered, and emotional needs are not discussed
- Cultural dimensions are understudied, and unaddressed in healthcare settings.

### PURPOSE

- The objective of the South Asian Family Approaches to Disease (SAFAD) study is to understand the cultural and psychosocial needs of South Asian survivors of breast cancer, and their informal caregivers (i.e., family and friends).

## COMMUNITY PARTNERS

### CRACK THE WELLNESS CODE

- An organization that aims to improve the wellbeing of South Asians in the San Francisco Bay Area through initiatives to educate, inspire, empower, and impact others.
- <https://crackthewellnesscode.org>

### INDIA COMMUNITY CENTER

- An organization that aims to promote Indian culture and values by providing social, cultural, recreational and community programs.
- <https://www.indiacc.org>

### COMMUNITY ADVISORY BOARD (CAB)

- A group of 8 South Asians who are diverse in occupations and are from the San Francisco Bay Area serve on the SAFAD study's CAB. CAB supports and guides the study to ensure that the study meet's the needs of the community and is culturally appropriate.
- <https://safadstudy.sites.stanford.edu/community-advisory-board>

## PROJECT DESCRIPTION

### STUDY DESIGN

- Mixed methods involving semi-structured interviews and surveys

### STUDY POPULATION

#### Breast Cancer Survivors

- Individuals who have had a breast cancer diagnosis, ≥18 years old, who self-identified as South Asian, received medical care in the California Bay Area

#### Informal Caregivers

- Relatives/friends who have cared for someone with a breast cancer diagnosis, ≥18 years old, and who self-identified as South Asian

### SEMI-STRUCTURED INTERVIEW DOMAINS

#### Cancer

- The history and diagnosis of breast cancer, the treatments considered, undergone, and planned, thoughts of mortality, and the participants' concerns of the future

#### Caregiving

- Survivor-caregiver relationship, caregiving in the US versus in South Asia, perceptions of paid care

#### Coping

- Coping strategies around breast cancer diagnosis, treatment, and experiences

#### Cultural Background & Medical Care

- The cultural needs, support, and experiences of participants in a healthcare setting

#### Home- & Community- Based Supports

- The home- and community-based resources used by participants when managing breast cancer

## Key findings

### South Asian survivors:

- Desire to connect with other South Asian survivors
- Are knowledgeable about their health condition
- Desire curated information from their care team
- Desire culturally tailored materials in native languages

### Informal caregivers:

- Are the primary information gatherers in the family
- Desire greater emotional and social support
- Should be asked about emotional needs by care teams

## Learn More About the SAFAD Study

<https://safadstudy.sites.Stanford.edu>



## Visit the Family & Mental Health Lab Website

<https://familymentalhealth.Stanford.edu>

## OUTCOMES

**Table 1.** Demographic Characteristics of Survivors (N=13)

Characteristics	Sample
Age, y	47.9 ± 9.1
Women (%)	13 (100.0)
Acculturation, %	
1 <sup>st</sup> generation	9 (69.2)
2 <sup>nd</sup> generation	2 (15.4)
Did not report	2 (15.4)
Breast Cancer Stage (%)*	
0	1 (7.7)
1	5 (38.5)
2	6 (46.2)
4	3 (23.1)

**Table 2.** Demographic Characteristics of Caregivers (N=13)

Characteristics	Sample
Age, years	43.9 ± 14.8
Women (%)	5 (38.5)
Acculturation (%)	
1 <sup>st</sup> generation	7 (53.4)
2 <sup>nd</sup> generation	2 (15.4)
Did not report	4 (30.8)
Relation to Survivor (%)	
Significant Other	7 (53.4)
Sibling	2 (15.4)
Child	3 (23.1)
Friend	1 (7.7)

\*Note: 2 survivors were diagnosed with breast cancer twice

## LESSONS LEARNED

- Breast cancer among South Asians is challenging to study partially due to stigma
- Community talks through our partners CWC and ICC were well-attended
- Developing a study-specific advisory board was crucial to the study's success

## RECOMMENDATIONS

- Create culturally tailored, curated information around cancer
- Develop programs to facilitate emotional support for South Asian breast cancer survivors
- Educate care teams in the importance of assessing unmet needs of caregivers
- Develop public health programs to reduce stigma

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