



## AUTHORS

**Akanksha Jain**, BS; Ambri Pukhraj, MS; Shreya Desai, MS; Rishabh Shah, BS; Rashmi Risbud, MA; Lidia Schapira, MD; Dolores Gallagher-Thompson, PhD; Karl Lorenz, MD, MSHS; Ranak Trivedi, PhD

## TITLE

Understanding the Care Networks of Informal Caregivers of South Asians with Breast Cancer using Atlas CareMaps

## ABSTRACT

Breast cancer rates are increasing among individuals with a South Asian heritage, i.e., from India, Pakistan, Nepal, Bhutan, Sri Lanka, Maldives, and Bangladesh. Informal caregiving is vastly understudied among this population, despite being influenced by cultural mores such as collectivism, cancer-related stigma, and gender roles. The South Asian Family Approaches to Disease (SAFAD) study took a mixed-methods, observational approach to describe the care networks of informal caregivers via an adapted version of Atlas CareMaps.

SAFAD collaborated with Crack the Wellness Code (<https://crackthewellnesscode.org>), the Indian Community Center (<https://www.indiacc.org>), and our Community Advisory Board (a group of professionals from different fields). Thirteen caregivers (43.9y(+/-14.8)) were interviewed (6 husbands, 1 wife, 3 children, 1 sibling, 1 friend). Semi-structured interviews were designed to develop an adapted Atlas CareMap, a visual representation of the caregivers' care network at the time of the survivors' caregiving. Atlas CareMaps depicted the people supported by caregivers, those who support the caregiver; their relationship; the frequency, intensity, type of care, and modes of communication used.

Results indicated that: 1) caregivers reported 9.2(+/-3.2) individuals in their care network, provided care to 3.8(+/-1.9) individuals, and received care from 7.7(+/-3.1) individuals; 2) caregivers primarily received emotional support from others; 3) their survivors' care teams were often included as a source of support and medical knowledge for survivors, but only three noted that the care teams supported them directly. Describing these networks is a key step to developing culturally-concordant programs that can support South Asian caregivers, even as they care for breast cancer survivors.

FUNDER: Cambia Health Foundation, Stanford Primary Care and Population Health, and the Khuller family.

## COMMUNITY PARTNER

Crack The Wellness Code

## CATEGORY

Improving Health Equity, Healthcare Access, Service, and Quality