

OVERVIEW

It is estimated that about 34,000 women are diagnosed annually with cancer in the south Indian state of Karnataka. Most of these are breast and cervical cancers so the overall five-year survival rate is between 73% to 89%. Assuming an overall 81% overall 5-year survival rate, the state would have more than 137,000 women cancer survivors in any year. In India, there is almost no active follow-up for patients who survive cancer treatment and almost nothing is known about their physical and mental health, and overall quality of life.

Study Objective: To examine the lived experiences and health needs of women cancer survivors in South India.

Study Design: The proposed qualitative study will use community based participatory methods to explore the lived experience and perspectives of 20 women cancer survivors and 5 caregivers. This will be done in two parts- through semi-structured interviews (Part 1) and photovoice (Part 2).

Study Site: The study will be carried out in Mysore, India, the second largest city in the south Indian state of Karnataka. Mysore has a population of 920,550. Approximately 73.6% of the city's residents are Hindus, 21.9% are Muslims, 2.8% are Christians, and the remainder have other religions. The literacy rate for the entire city is 87.7%, and Kannada is the most widely spoken regional language. Approximately 1 in 5 residents live below the poverty line.

Setting: Public Health Research Institute of India (PHRII) is a Charitable Trust engaging in both public health research and social service. It is recognized by the Department of Science and Technology (DST) of Government of India as a 'Scientific and Industrial Research Organization' (SIRO). In addition to its decade long research portfolio, PHRII operates the Prerana Health Clinic and laboratory, offering free outpatient healthcare services and prevention programs to low-income communities in Mysore. PHRII has 27 full-time employees including physicians, nurses, counselors, laboratory staff, outreach workers, study recruiters, data entry operators, development officer, and administrative staff. The institute has a full-service diagnostic laboratory offering microbiology, serology, pathology, and molecular diagnostic services. Dr. Madhivanan has collaborated with PHRII since 2005 on studies funded by the NIH/NICHD, ICMR, and various foundations located in the U.S and the U.K. PHRII is also a recognized NIH training site for Global Health Research. We plan to build the current research using the existing infrastructure and experience developed by our study team. PHRII has a Community Advisory Board, Institutional Ethics Committee registered with the Health and Human Services with a FWA assurance.

Summary of Grant Deliverables

The over-arching goal of the AACE Reads Project was to conduct formative research to understand the lived experiences and health needs of women cancer survivors in South India. This study was completed successfully in the grant time period. The study findings were presented as a photo exhibition for the community on June 4th 2023 that was attended by 85 community members. In addition, the study findings were presented at four medical institutions as invited talks to disseminate the findings of the study.

We had to present the study to the PHRII Community Advisory Board in a full meeting that reviewed all planned trainings, materials, and activities. We hired and trained four public health students from JSS AHER School of Public Health and five PHRII staff members in community based participatory research

methodology and Photovoice. We met with stakeholders in Mysore District including Panchayat Leaders, Community health workers, Community Based Organizations working in women's health, the District Health Officer, Taluk Medical Officer, and medical care providers at three major hospitals providing medical care for cancer patients to inform them about the program and coordinate services and referrals. We contacted all the PHRII study participants with cervical and breast cancer who had agreed to be contacted for future studies. Additionally, we also invited cancer survivors through the health care institutions.

Results

- Hired and trained nine project staff to carry out the program in Mysore;
 - Trainings were conducted on the following topics:
 - MODULE 1 Introduction to Cervical and Breast Cancer
 - MODULE 2 Overview of Qualitative Research Methods
 - MODULE 3 Community Based Participatory Research including Photovoice
 - MODULE 4 Research Ethics
 - MODULE 5 Photography
- Identified, evaluated and enrolled 23 participants from Mysore District which included 12 breast and 7 cervical cancer survivors and 4 care givers;
- Conducted 15 semi-structured interviews of cancer survivors and their caregivers. Cancer caregivers were invited by cancer survivors to speak to the research staff regarding for participation in the study.
- All 23 participants were trained and participated in the photovoice sessions. We had an introductory session followed by three additional sessions to identify themes, select photos, voted on the photos to select the best photos and quotes to be included as part of the advocacy package and call to action.

Lessons Learnt

- The major themes based on the rapid analysis of the discussions and photos included: Lack of education and information; Lack of family and social support; Cancer stigma.
- The participants were very enthusiastic and were interested in serving as spokespersons to increase cancer screening and helping with triage.
- Many of the participants from the rural regions were facing a lot of financial distress due to lack of information on the kind of financial support available through the government and having to travel long distances with attendants leading to expenses not covered under insurance for treatment and follow-up care.
- Participants were also interested in getting skills training to increase their employment opportunities. We contacted the development agencies to connect cancer survivors for training and support to increase their chances for employment.
- We were able to raise money to purchase livestock for a participant who had lost her home and the only two goats that were her emotional support to go through her cancer treatment. We also raised enough funds to pay for fodder, medications for the two baby goats for a period of one year to reduce financial issues.

- The Mayor of Mysore attended the Photo Exhibition and committed to resources to increase screening and support for cervical and breast cancer.
- The president of JSSAHER committed resources to provide social support and counselling services at the new comprehensive cancer control center that they are planning to start shortly.

Impact of receiving this grant on the PIs' careers

This study helped PI to build collaborations at multiple cancer centers and hospitals in Mysore. In addition, the pilot data generated from this study will help apply for a NIH grant to plan an intervention study to address some of the themes identified from this study.

Plans for future Publication.

Findings from the study were submitted as an abstract to the AACE annual conference to be held from 3-6 October 2023 in Toronto. The abstract was accepted as an Oral presentation and was awarded the AACE Endowment Award of \$1000 to the PI. The plan is to submit a manuscript to the Journal of Cancer Education in Spring of 2024.

Project Dissemination:

1. Madhivanan, P. (2023, September) *Cervical Cancer Control and Prevention*. Invited Lecture, The Infectious Disease Epidemiology and Applied Studies Initiative & USC IGH, Keck School of Medicine of University of Southern California, Los Angeles, USA. September 11, 2023
2. Madhivanan, P. (2023, July) *Bridging the gap from cancer screening to survivorship: Mysuru Experience*. Invited Lecture, JSS Hospital, JSS Academy of Higher Education and Research, Mysuru, India, July 14, 2023
3. Madhivanan, P. (2023, May) *Towards Elimination of Cervical Cancer by 2030: A Public Health Strategy for India*. Invited Talk, PSG Institute of Medical Sciences and Research, Coimbatore, India, May 26, 2023
4. Madhivanan, P. (2023, May) *Challenges in Prevention and Control of Cervical Cancer: A Public Health Perspective*. Invited talk, GITAM University, Vishakapatnam, India, May 5, 2023