

A Pilot Study to Assess the Experience of Stigma in Women with Breast Cancer

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ORGANIZATION

- Aga Khan University Hospital in Nairobi, Kenya (AKUH) strives for excellence in health care through the provision of accessible, compassionate, and evidence-based care

BACKGROUND/RATIONALE OF PROJECT

- Investigate the effects of breast cancer stigma on the mental and physical health outcomes of women with breast cancer in Nairobi, Kenya
- Breast cancer is the most common cancer type in Kenya, with a prevalence of 6,000 new cases and 2,500 cancer-related deaths each year
- The negative perceptions of breasts with sexuality and motherhood can make women fearful of stigma and can have detrimental effects on their mental health, quality of life, and use of health care services

OTHER COMMUNITY PARTNERS INVOLVED

- This research will take advantage of the existing collaboration between researchers at the University of Alabama at Birmingham and at AKUH

LESSONS LEARNED

- The importance of structured communication when working virtually
- How to clearly condense information into training materials

I crafted and delivered clear and concise interview training materials. I conducted in-depth interviews with health care professionals.

Agenda, Day 2 (July 28, 2021)

- Qualitative Interviewing - methodology, tips
- Informed Consent
- Review of Interview Guides (BC patients, family members, healthcare providers)
- Logistics
- Q&A

FOR HEALTHCARE PROVIDERS:

I. INTRODUCTION

My name is _____. I am working with Aga Khan University Hospital and the University of Alabama at Birmingham (UAB) on a study aiming to understand experiences with breast cancer. I would like to talk to you about your experience as a healthcare worker providing care to women diagnosed and treated for breast cancer. Some questions will also ask about community perceptions of your patients and their support. The information that you provide will be used to improve services for patients with breast cancer. As you learned during the consent process, this discussion is scheduled to last around one hour and at most one and a half hours. If you have questions on other topics, I can assist you to find answers after the interview is over. Remember whatever you say in this interview will be kept confidential.

(Confirm that the participant has consented to the audio recording of the discussion and only start the tape recorder AFTER any identifying information has been shared. This guide includes the topics to be covered and questions that may be helpful in facilitating the discussion. You do NOT have to ask all the questions or follow the order given in the guide. Major topic areas and questions are indicated in **Bold**.)

COMMUNITY IMPACT

- This study will be used to obtain a comprehensive understanding of the experiences, mechanisms, and effects of breast cancer stigma in resource constrained settings
- Findings from this study can be used to design interventions to address breast cancer stigma and improve health outcomes in Kenya and similar settings globally

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