Identifying And Mitigating Cancer Associated Distress In Patients with Breast Cancer In Kenya-a Partnership between Academia, Patients and Community Organizations.

Karishma Sharma
Aga Khan University Hospital, Kenya

Executive summary

Objectives
To address the adverse impact of breast stigma on women and their families and design effective interventions.

Activities
We conducted a survey of women with breast cancer from across various socio-economic backgrounds and diverse geographic regions in Kenya. For this study we partnered with 3 major cancer support organizations that serve and support women with breast cancer across Kenya: (1) *The Faraja Cancer Support Trust, (2) A Fresh Chapter and (3) The Ismaili Community*

Outcomes
We developed a survey with validated content that had been used by our group and surveyed a total of 132 breast cancer patients (45 from each partner organization) on the perceptions of stigma, psychosocial determinants, quality of life, and sources and impact of stigma. Patients were above the age of 18 years and had either current or history of breast cancer. Our findings revealed that patients with breast cancer frequently experienced stigma. High stigma scores were associated with increased rates of depression and anxiety. Those experiencing stigma had an overall inferior quality of life.

Challenge

Mental health and stigma in patients with breast cancer, especially in the African context, has been understudied. Our study has highlighted key areas that impact the overall wellbeing of breast cancer patients living in the community.

Some of the key findings include:

1. **Impact on Mental Health**: Our study highlighted that breast cancer patients had high stigma scores, and this contributed to high levels of depression and anxiety which was impacting their mental health and overall quality of life.
2. **Impact on physical functioning**: Breast cancer patients experiencing anxiety and depression were more likely to complain of fatigue, low appetite and insomnia.
3. **Financial distress** was a major factor that contributed to depression and anxiety among our study participants.
4. **Impact on Quality of Life and social support**: Each additional unit of breast cancer stigma scale score was associated with a -0.54 % decrease in Health-related Quality of Life (EORTC QLQ-C30) when adjusted for Breast Cancer Stage, Income, Social Support, Financial Score, and Pain Rating. This effect was statistically significant (t = -4.2, df = 116, p = 0.0001).

Direct involvement of patient experts

Activity	Output
Training of lay volunteer CSBs (Champion Stigma Busters).	• 2-3 CSBs from each partner cancer support organization were trained on basic breast cancer knowledge (prevention, early detection, treatment) , participant recruitment, survey conduct and data collection . • They were trained to identify patients who would need counseling for to mental health services. • They were responsible for creating awareness about the study within the partner organization and facilitated the design of the marketing/promotional material.
Participants (breast cancer patients) who met the eligibility criteria and consented to the study were surveyed by the CSB's	• The data from the survey identified key sources of stigma for women with breast cancer and collated common themes contributing to the experience of stigma e.g. socio-cultural and institutional factors, as well as factors associated with the impact of the diagnosis and treatment of breast cancer. • This data will inform recommendations for subsequent follow-up projects, including programs and policy proposals aimed at reducing stigma amongst breast cancer patients. • The data has also been shared with the respective patient cancer support organizations for them to incorporate within their support group programs and to implement activities that promote resilience and reduce stigma in women with breast cancer.

Incorporating feedback

Key findings from the data analysis:

1. **Stigma and Depression**: Higher levels of stigma were associated with significantly increased rates of depression (p < 0.001). The stigma scores for individuals with depression were notably higher than those without depression.
2. **Stigma and Anxiety**: There was a strong association between stigma and anxiety. Higher stigma scores correlated with increased anxiety symptoms (p < 0.001).
3. **Impact on Quality of Life**: Stigma negatively affected health-related quality of life, particularly in areas such as fatigue, pain, social functioning, and global health status (p < 0.001 for multiple comparisons). There was an inverse correlation between stigma score and quality of life parameters. For each incremental increase in stigma score there was a -0.54 % decrease in quality of life.
4. **Social and Physical Functioning**: Social support levels differed significantly between those with higher and lower stigma. Participants with higher stigma reported lower levels of social and emotional support (p = 0.007). Stigma was also linked to greater physical health limitations and fatigue.

Impact on study design

1. **Relevance:** The data we collected from the Rising Tide grant made us focus on key factors that are contributors to stigma such as emotional distress (anxiety/depression), social isolation and discrimination experienced by patients with breast cancer in Kenya.
2. **Tailored interventions**: The findings and data from the study will be used to design a survivor-led, group-based, intervention program specifically aimed at reducing stigma, promoting resilience, and building self confidence among breast cancer patients.

conclusions

Our study has highlighted key areas that impact the overall wellbeing of women diagnosed with breast cancer in the community setting. Identifying these factors is fundamental to reducing the impact of stigma, advancing patient centered care and informing strategies that will foster a supportive and empathetic environment for all patients with breast cancer.

1 Applying for the pre-application grant

2 Activities proposed

3 Outcomes & incorporating them back into endpoint and trial design

Providing pre-application funding for patient involvement

A new grant mechanism called "pre-application grants" has been launched. These small grants are to close the funding gap for patient experts to provide input to the development of a grant application/protocol.

We are aiming at supporting patient organizations during this early phase with a budget. The budget should be planned to cover travel costs to preparatory meetings and the work time invested by staff or patient experts. This work should be carried out as a preparation step prior to the submission of a clinical research grant application to RTFCCR

4 Conclusion

RISING TIDE
Foundation for Clinical Cancer Research