

Patient Advocacy Approaches to Improving Care for Breast and Cervical Cancer in East and Southern Africa

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PURPOSE Breast and cervical cancer are the most common cancers among women in East and Southern Africa, where mortality remains high because of late diagnosis and limited access to treatment. We explored local approaches to breast and cervical cancer advocacy to identify the most pressing issues and opportunities for increasing the impact of civil society activities in the region.

METHODS Focus group discussions were conducted with participants of the 2016 Women's Empowerment Cancer Advocacy Network (WE CAN) Summit in Nairobi, Kenya. Discussions were audio-recorded, transcribed, coded, and analyzed for emergent themes. Results were presented to participants of 2019 WE CAN summit for cross-validation.

RESULTS Four focus group discussions were conducted with 50 participants. Thirty-six (70%) identified as advocates, 30 (59%) as cancer survivors, 14 (27%) as nongovernmental organization representatives, 13 (25%) as researchers, 4 (8%) as clinicians, and 6 (8%) as policymakers. Although most participants focused on cancer awareness and screening/early detection, some noted that treatment was often unavailable and advocated for a broader strategy to improving access to care. Challenges to designing and implementing such a strategy included knowledge gaps in addressing late diagnosis and access to care, difficulty collaborating with like-minded organizations, approaching policymakers, and addressing treatment financing. Cancer coalitions, although rare, were crucial to building collaborations with ministries of health, policymakers, and international organizations that advanced breast and cervical cancer care.

CONCLUSION Participants indicated that they would benefit from additional training about resource-appropriate best practices for improving breast and cervical cancer care and outcomes. Coalition-building and collaborations, including with oncologists and other medical professionals involved in cancer care, were crucial to leveraging limited resources, sharing lessons learned, and developing local solutions to common challenges.

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INTRODUCTION

Cervical and breast cancer are the most common cancers and the top two causes of cancer-related deaths among women in East and Southern Africa. In 2018, there were an estimated 67,042 new cases of breast cancer and 43,497 cervical cancer deaths as well as 55,130 new cases of breast cancer and 25,167 breast cancer deaths in the region.¹ High case fatality has been attributed to late-stage diagnosis and limited access to treatment as a result of patient and health system factors (Fig 1).²⁻²⁰

Patient advocacy has played a key role in improving cancer care in high-income countries.²¹ Although advocacy is gaining visibility in the region, oncologists and other medical professionals involved in cancer early detection and treatment may not be aware of the

benefits of supporting patient advocates and partnering with them. In 2011, the African Organization for Research and Training in Cancer (AORTIC) published recommendations for best practices in political, education, research, fundraising, support, and community advocacy in Africa.¹³ A survey of advocacy organization in Africa by AORTIC found that 90% were involved in raising awareness, 64% provided patient support, 46% conducted fundraisers, 44% engaged in policy advocacy, and 72% engaged in research.²²

A greater awareness of the strength and resources that breast and cervical cancer advocacy organizations possess, as well as of the challenges they face, may contribute to new collaborations between advocates and clinicians and lead to downstaging and improved cancer outcomes.

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CONTEXT

Key Objective

To explore strengths and opportunities in breast and cervical cancer patient advocacy in East and Southern Africa.

Knowledge Generated

Patient advocacy organizations have had some successes in raising awareness, screening/early detection, patient support, and building collaborations, and have great potential to contribute to improving cancer outcomes in the region if the following challenges are addressed: low knowledge about best practices in early detection and scaling up access to treatment and need for greater collaboration with like-minded organizations, clinicians, and policymakers to leverage limited resources.

Relevance

We provide recommendations about how clinicians working in cancer care in the region and regional and international cancer organizations can partner together with patient advocacy civil society to leverage resources and experience to improve breast and cervical cancer outcomes in the region. Our findings may be applicable to other low-resource settings.

At the request of local advocates, the Women's Empowerment Cancer Advocacy Network (WE CAN) organized the first East and Southern Africa WE CAN Breast and Cervical Cancer Advocacy Summit in Kampala, Uganda. WE CAN, based at the University of Washington, fosters regional networks of breast and cervical cancer advocates to connect stakeholders, facilitate exchange of best practices, improve knowledge, and build advocacy capacity. Summits bring together advocates, clinicians involved in cancer care, and policymakers to increase awareness of barriers to care and strengthen linkages among stakeholders engaged in advancing cancer care.²³

At the 2016 WE CAN Summit in Nairobi, Kenya, we explored the most pressing issues in breast and cervical

cancer advocacy in the region as well as strengths and challenges in addressing these from the point of view of summit participants.

METHODS

Focus group discussions (FGDs) were conducted with attendees of the 3rd Annual East and Southern Africa WE CAN Summit in Nairobi, Kenya in 2016 using an open-ended interview guide.²⁴ FGDs were audio-recorded and transcribed verbatim. A code book was created based on both themes from the questions and those that emerged from responses.²⁵ The transcripts were double-coded; codes were extracted and analyzed for prevailing patterns and relationships between themes.²⁶ Key themes are

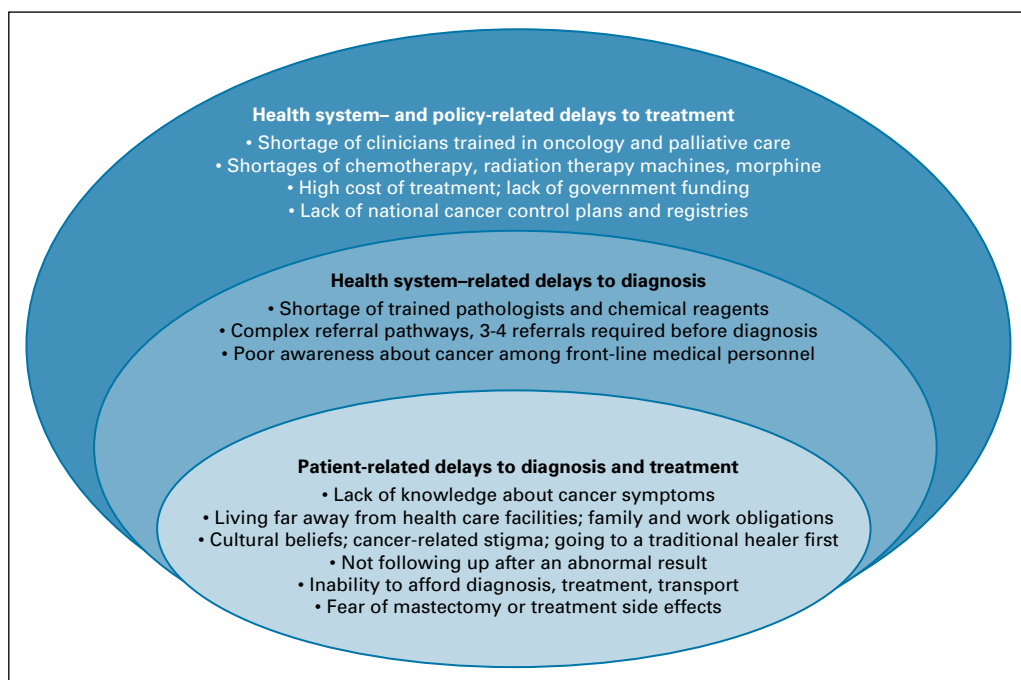


FIG 1. Delays to breast and cervical cancer diagnosis and treatment.

presented with representative quotes. Results were presented to participants of a subsequent WE CAN summit for cross-validation and suggestions for future research.

Study procedures were approved by the institutional review board at the University of Washington School of Medicine. All study participants provided written informed consent. Travel and accommodations were provided for all participants who traveled from outside of Kenya.

RESULTS

Participant Characteristics

Four focus groups were conducted with 50 participants from nine countries: Ethiopia (n = 2), Kenya (n = 32), Malawi (n = 2), South Africa (n = 1), Rwanda (n = 4), Tanzania (n = 2), Uganda (n = 3), Zambia (n = 3), and Zimbabwe (n = 1). Participants identified as advocates (70%), cancer survivors (59%), nongovernmental organization (NGO) representatives (27%), researchers (25%), clinicians (8%), and government/policy (8%).

Key Themes

Themes that emerged clearly from the data included: a focus on raising awareness and promoting screening despite limited access to care, knowledge gaps related to best practices in addressing barriers to early diagnosis and treatment in low-resource settings, and the strengths and limitations of collaborations and coalitions in improving cancer care.

Ethical dilemma: conflict between screening and limited access to care. Many participants described their activities to promote breast cancer awareness yet struggled with how to address limited access to care. Messages on the importance of timely diagnosis and accessible treatment were not as prevalent, while delays in presentation were assumed to be the result of limited knowledge rather than structural barriers. Several participants expressed concern about the ethics of promoting awareness and screening when treatment was not accessible, while others emphasized that advocacy for broader access to treatment was urgently needed.

“Our patients are suffering, because they can’t afford the treatment. Most of the energies are based on our screening. We pretend that [the government] can afford to give health care to every citizen in the country, but they aren’t.”

“We have been able to organize four cancer walks in our town. And we do the breast and cervical cancer screening. We have a lady who could not afford her treatment, and so as group we contributed, we had her go through the surgery, but she has never been able to pay for her chemotherapy, radiotherapy.”

“We do education awareness mostly in the urban areas, because it is disadvantaged to educate somebody in a rural area who doesn’t have access to treatment.”

“We like to focus on prevention, screening. It’s the same with government... they need to be pushed on more difficult

challenges. Because breast cancer is perceived as being so complicated to do surgery, to do chemo, they’ve just forgotten about it.”

Limited knowledge of best practices in addressing access barriers and scaling cancer care. Participants were experienced in organizing awareness campaigns and providing financial and psychosocial support to patients and families. Common challenges in advocating for expanding access to care included uncertainty about appropriate policy solutions as well as about how to engage other stakeholders and address high drug prices and personnel shortages.

“How do a group of us engage the Pharmaceutical and Poisons Board... Do we actually know what the process is, who do we need to engage, that I think would be a more effective use of our advocacy, because this is why our patients drop out; it’s fine to do screening, it’s fine to do awareness but then what?”

“There are no clear working structures, how we engage with government, how we engage with fellow organizations working in cancer. As opposed to us coordinating and cooperating together there’s more of competition.”

However, other participants shared stories of successfully engaging stakeholders to achieve results and gain respect and a seat at the table.

“When we started, PAP smears cost 3,500. We talked to some of the pathology labs to reduce their cost. Then we talked to the gynecologists to give lower rates for consultation. When we started, we were considered the women’s group that’s doing something about cervical cancer. Today we sit at tables with government officials where policy is being influenced.”

Benefits and limitations of collaboration and coalitions in advancing advocacy efforts. Collaborations between survivors, community groups, health ministries, and health care professionals were built around raising awareness, screening/early diagnosis, and patient support.

“We have a lot of women’s groups. They meet after church, so we go to women’s groups and talk to them, teach them how to do self-breast examination [BSE]. And then we also go to organization like corporate. We talk to their employees about how to do a BSE.”

“We collaborate with the Ministry of Health, we mobilize for screening, we sensitize the communities and then the Ministry of Health comes in, do the screening, because they are the ones with the resources and the technical expertise.”

Through awareness campaigns, some participants were able to create greater demand for oncology services. Others educated front-line medical workers about cancer symptoms to promote early diagnosis.

“If we are talking to community health workers, we train them on what are the signs and symptoms of cervical cancer, breast cancer, and how to effectively refer women to a clinic. We also to ensure that all traditional healers are oriented on the signs and symptoms of breast cancer.”

Because we know that our women mostly in the rural areas, the first person they go to is a traditional healer."

"When we got started, the cancer ward was empty. If you walk into our cancer hospital, it actually takes almost the whole day for a patient to be seen. So we have created that demand through our awareness campaigns, outreach programs.

Participants relied on oncologists to provide them with accurate information about cancer care and to participate in their early detection campaigns, thus lending them credibility. A few expressed a hope for closer collaboration with clinicians to provide timely informational and psychosocial support to patients and train front-line clinicians about breast and cervical cancer signs and symptoms and appropriate referral pathways.

"You don't know how to describe what all of the medical terms are. But through interaction with people in the medical field we're able to get that knowledge. We've come up with a quick guide for anyone to just be able to do, whether it's their breast self-exam, cervical screening."

Collaborations to advocate for implementing a national cancer control plan, a cervical cancer screen and treat program, or negotiating drug prices were effective but rare and required broad collaboration from a variety of stakeholders, including clinicians.

"My group comprises of breast cancer survivors, medical practitioners, well-wishers, and supporters. We felt like we should come up together and see if we could pressure the government to see the need to have a cancer hospital. Fortunately, we are actually going to have 230-bed capacity to be opened next month. "

Such coalitions were focused on improving early detection and care for all cancers and also uniting groups advocating for palliative care and tobacco control. Among participants who were part of a cancer coalition, there was consensus about the value of building coalitions and recognition that it took time and work to build trust among members. Participants credited outside and/or neutral parties, including international organizations, as key facilitators in initially bringing multiple groups together. Participants identified networking and educational opportunities, such as WE CAN summits, as valuable to building collaborations with other advocates, clinicians, and policymakers, as well as generating new ideas.

"We have a Knowledge Share, where an organization either volunteers to say what is working, and, 'This is what we're working on,' or another organization comes and says, 'We attended this conference, and this is what we took out of it.'"

"It took a whole year to define what we wanted to see in the coalition. It was meetings on meetings...when you are forming a coalition, there is the element of trust.... The alliance is not there to eat up the organizations. It's there to strengthen them."

"We thank the Ministry of Health, because one time they called a few people whom they've been frequently working

with. So that is the time we teamed up with [volunteer].... We were able to come up together and bring together all our ideas."

"There was a lot of mistrust, fearing that they'll tap into your sponsors. But with the coming of the [international organizations]...they encouraged us saying...it will be very difficult to support individual organizations. And we formed an umbrella body. And through that we received funding."

Validation of Results and Future Research

Results were presented to participants of the 2019 WE CAN Summit in Johannesburg, South Africa, who agreed with the findings. Thirty-six (85.8%) responded to the question about what cancer-related research question they would like addressed in their community, including: barriers to care (21.6%); cervical cancer/human papillomavirus vaccination (21.6%); impact of stigma, culture, and religion in cancer (16.2%); needs of survivors (13.5%); evidence-based patient navigation (8.1%); impact of cancer campaigns (8.1%); needs of patients with metastatic cancer (5.4%); and impact of sexuality on patient needs (5.4%).

DISCUSSION

Patient advocates are a source of invaluable insight into patient needs and specific local barriers to care—both prerequisites to implementing effective, culturally appropriate, and sustainable interventions tailored to local resources. They can be strong allies of and advocates for the medical community, sharing their knowledge and experience and bringing data to life with compelling stories. Advocates and clinicians can achieve greater impact through collaboration and together can compel their governments and ministries of health to make a commitment to improving access to affordable cancer care.

Limited attention has been given to the role and value of breast and cervical cancer advocacy in Africa beyond the write-up of AORTIC workshops in 2009 and 2011.^{13,22} We describe the most pressing issues in breast and cervical advocacy in East and Southern Africa as perceived by participants of the 2016 WE CAN Summit in Nairobi, Kenya.

Key challenges identified by participants included: expanding knowledge of resource-appropriate and locally relevant best practices for improving early diagnosis and access to treatment, including palliative care; negotiating drug prices and health care financing; health care personnel training; and coalition building and effectively engaging decision makers. On the basis of results of multiple studies addressing the health care infrastructure in the region,^{2-12,15-20,27} oncologists and other clinicians involved in cancer care likely face similar challenges. By partnering with patient organizations, clinicians could provide invaluable assistance to patient advocates by sharing their medical knowledge and experience, work with patient advocates to improve informational and psychosocial support their patients receive, and address broader structural barriers to early detection and treatment.

TABLE 1. Selected Advocacy Resources and Tool Kits

Organization	Materials	Hyperlink
ABC Global Alliance	Information on metastatic breast cancer	www.abcglobalalliance.org
AORTIC	Cancer advocacy training toolkit	www.uicc.org/sites/main/files/atoms/files/AdvocacyToolkit%28Web%29_0.pdf
BCI2.5	Knowledge summaries for comprehensive breast cancer control, global breast health analytics map	www.bci25.org
ESMO	Cancer in Africa advocacy resources	www.esmo.org/Policy/Cancer-Prevention-Initiatives/Cancer-Prevention-4-Africa
ICCP	International Cancer Control Partnership	www.iccp-portal.org
NCCN	Harmonized treatment guidelines	www.nccn.org/harmonized/default.aspx
NCD Alliance	Resources and toolkits for NCDs and coalitions	ncdalliance.org
UICC	Cancer advocacy resources (SPARC, Treatment of All)	www.uicc.org/advocacy-resources-guide
WE CAN	Women's cancer's advocacy resources	www.womenscanceradvocacy.net/en/resources.html
WHO	Guide to early diagnosis	www.who.int/cancer/publications/cancer_early_diagnosis/en

Abbreviations: AORTIC, African Organization for Research and Training in Cancer; BCI2.5, Breast Cancer Initiative 2.5; ESMO, European Society for Medical Oncology; NCCN National Comprehensive Cancer Network; NCD, noncommunicable disease; SPARC, Seeding Progress and Resources for the Cancer Community; UICC, Union for International Cancer Control; WE CAN, Women's Empowerment Cancer Advocacy Network.

Our study found that some of AORTIC's advocacy best practices recommendations have been adopted with positive results. A few participants formed collaborations and coalitions to exchange ideas, leverage resources, and magnify impact, including by working together with local clinicians and ministries of health. Organizations received advocacy training and technical support from regional and international cancer organizations. Donors are adopting funding models that encourage collaboration rather than competition. Advocates are participating in research projects together with local clinicians to improve cancer care. However, despite recommendations from AORTIC¹³ and WHO²⁶ that breast cancer screening not be conducted without access to treatment, organizations continue to focus on screening. In the case of breast cancer, our findings, as well as post-conference knowledge checks from the WE CAN conferences in Zambia in 2018 and Rwanda in 2017, indicate that there continues to be confusion regarding the terminology and evidence behind early detection ("education to promote early diagnosis and screening" per WHO²⁷), early diagnosis (examination of symptomatic patients), and screening (examination of asymptomatic patients).

Proposed strategies for improving outcomes for breast and cervical cancer in the region include building sustainable partnerships and coalitions to facilitate early detection and access to affordable treatment of early-stage disease.^{28,29} Lessons from the HIV epidemic, where improved awareness and access to care facilitated earlier diagnosis and treatment adherence, can be used to advocate for expanded access to cancer care, including through integration with maternal health and HIV treatment programs.^{30,31}

AORTIC, WHO, Union for International Cancer Control (UICC), and WE CAN all provide online toolkits, courses, and information to support cancer advocacy. Online training about best practices to improve breast and cervical cancer outcomes include the resource-stratified guidelines by Breast Health Global Initiative (BHGI) and National Comprehensive Cancer Network, the Knowledge Summaries for Comprehensive Breast Cancer Control,³² Global Breast Health Analytics Map and assessment tools available from the Breast Cancer Initiative 2.5 platform,³³ and Web-based and in-person courses from the US National Cancer Institute, American Society for Clinical Oncology, UICC, and WHO.³⁴ Forums for exchanging ideas and building collaborations include AORTIC, WE CAN, and UICC (Table 1).

Patient advocacy will continue to play a key role in improving cancer care in the region. On the basis of participant input and prior research related to breast and cervical cancer in East and Southern Africa, the following may be helpful in advancing breast and cervical cancer advocacy in the region:

- Strengthened collaboration between patient advocates and clinicians to help downstage disease and improve access to affordable diagnosis and care through advocating for increased funding and compassionate use pharmaceutical programs;
- Continued dissemination of resources related to advocacy, cancer control planning and implementation, funding opportunities, and current research on breast and cervical cancer in the region;
- Technical assistance in building working relationships with government and the private sector, organizational development, and coalition building;

- Encouragement of collaborations and coalition building by ministries of health and international cancer organizations, including by prioritizing funding for projects that leverage resources through collaborating with other stakeholders;
- A sustainable forum for advocates to exchange, share experiences, and dialogue with other NGOs, ministry officials, oncologists and other clinicians involved in cancer care, policymakers, industry, regional and international cancer organizations, and researchers;
- Expanded engagement of advocates in the development and implementation of cancer control plans, including by providing advocates with any knowledge and training they may need to feel empowered to make meaningful and long-lasting contributions;
- Continued focus on phased implementation strategies based on available resources and dissemination of evidence supporting breast cancer early diagnosis versus screening;
- Support for research that includes and considers the priorities of patient advocates and survivors in the region;
- Increased opportunities and access to training on policy advocacy, broader policy landscape, human resource needs for health, and drug pricing.

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Our study had several limitations. Participation was limited to individuals attending the WE CAN Kenya summit, whose views may not be representative of all breast and cervical cancer advocates in the region. Furthermore, 64% of the participants were from Kenya, which may limit the adaptability of these results. Exploration of the views of oncologists and other clinicians involved in breast and cervical cancer care should be pursued in future research studies to highlight unique challenges faced by clinicians and further elucidate the potential for collaboration and partnership with patient advocacy organizations.

In conclusion, breast and cervical cancer advocates in East and Southern Africa have had some notable successes in raising awareness, screening/early detection, and patient support. Participants indicated that they would benefit from additional tools and technical assistance to help tackle the next key challenge of improving and scaling up access to affordable treatment. Collaboration and coalitions, both in-country and across borders, were crucial to sharing lessons learned and developing local solutions to common challenges. Oncologists can provide invaluable help to patient advocates by sharing their medical knowledge and working together to address existing structural barriers to care.

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