

The availability of breast cancer screening, diagnostic and treatment services and integration with HIV-related care in Sub-Saharan Africa: Results from an electronic survey

Naomi Lince-Deroche^{1*}, Tembeka Sineke¹, Faith Moyo¹, Cynthia Firnhaber^{2,3}, Sarah Rayne^{4,5}

¹ Health Economics and Epidemiology Research Office, Department of Internal Medicine, School of Clinical Medicine, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

² Right to Care, Johannesburg, South Africa

³ Clinical HIV Research Unit, Department of Internal Medicine, Faculty of Health Sciences, University of Witwatersrand, Johannesburg, South Africa

⁴ Helen Joseph Breast Care Clinic, Helen Joseph Hospital, Johannesburg, South Africa

⁵ Department of Surgery, School of Clinical Medicine, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

*Corresponding author: Naomi Lince-Deroche, naomi.lince.deroche@gmail.com, Johannesburg, South Africa, +27 10 001 7930

ABSTRACT

Background

Breast cancer and breast disease are often excluded from sexual reproductive health advocacy resulting in missed opportunities for advancing breast care services and engaging patients holistically.

Objectives

We aimed to determine the availability of diagnostic and treatment services for breast disease and integration with HIV-related care in Sub-Saharan Africa with a special focus on South Africa.

Methods

We conducted an online self-administered survey from July 2015-February 2016. We used convenience sampling to identify potential respondents, i.e. experts knowledgeable about breast care service availability in their respective countries. Secretariats of clinical societies circulated the survey link to members. Survey questions included: health facilities where respondents worked, breast care services available, whether s/he could refer for breast care services, and whether HIV care was integrated with breast care services. Survey results were analysed in Stata and presented as simple proportions representing non-missing responses.

Results

Approximately 800 hundred individuals received the survey; 112 opened the link; and 99 (88.4%) completed the survey. Nineteen (19.2%) respondents were located in South Africa; 78 (78.8%) were medical doctors. Overall, 88 (88.9%) respondents indicated availability of at least one type of breast disease service at their place(s) of work; however, access to advanced screening and treatment were less common. Thirty-five (35.4%) of respondents indicated that HIV-related services were available for breast care patients at their place(s) of work; 18 (51.4%) of these indicated that HIV and breast care were offered by the same staff.

Conclusion

Although availability of at least one type of breast care service was high; comprehensive breast care availability was less common, as was integration with HIV services. Fragmented care may have implications for efficient management of breast disease.

INTRODUCTION

Breast cancer is the most commonly diagnosed cancer among women.^[1] Each year nearly 1.7 million women are diagnosed and over 500,000 die from the disease globally.^[2] The burden of disease is particularly high in Sub-Saharan Africa where annually over 94,000 women are diagnosed with breast cancer and over 47,000 die from the disease.^[2] Further, breast cancer represents just a small proportion of all breast disease. In a 2013 study in Nigeria and Uganda, between 70 to 80 percent of breast lumps were found to be benign fibroadenoma or fibrocystic changes.^[3] A recent study in South Africa showed that among 354 women who presented with breast-related complaints at a comprehensive breast care clinic over a 14 month period, just 14.6% ultimately received a diagnosis of breast cancer.^[4] Several men with breast related complaints also attended the clinic during the study;^[4] gynecomastia among men is not an uncommonly diagnosed condition in South Africa given high levels of Efavirenz –containing antiretroviral therapy among HIV-positive men.^[5,6] In addition, although uncommon, a number of men are diagnosed with breast cancer in South Africa annually. In 2011, the last year for which data are available, 145 men were diagnosed with breast cancer.^[7]

Despite obvious links between breast cancer, breast disease, and women's SRH, the World Health Organization (WHO) does not include breast care services among its priority list of SRH interventions.^[8] Breast care is also absent from guidelines recently released by the WHO for the comprehensive management of HIV-positive women's sexual and reproductive health care needs.^[9] The failure to recognize breast care as an SRH issue has been previously noted as a missed opportunity for increasing awareness and early detection of breast cancer.^[8] Also, the need for integration of SRH and services has been recognized globally – as an HIV prevention and management strategy – since the mid-2000s.^[10,11] Thus excluding breast care services from SRH also reduces opportunities for counselling on the importance of HIV testing and treatment.

Despite the burden the disease, there is a dearth of data on the availability of breast care screening and treatment services in Sub-Saharan Africa, and there is almost no information on the integration of HIV and breast care services in this setting. In this study we aimed to assess the availability of comprehensive breast care services and their integration (or not) with HIV care and treatment services in Sub-Saharan Africa, with a special focus on South Africa which has placed an emphasis on integration of HIV and SRH care in its public facilities.

METHODS

Study design and data collection

We used Survey Monkey (Survey Monkey Inc. San Mateo, California, USA) to conduct an online, self-administered survey between July 2015 and February 2016 with breast care ‘experts’ from Sub-Saharan African, including South Africa. We considered ‘experts’ to be individuals with knowledge on breast care services and staffing in their respective countries.

We used convenience sampling to identify potential respondents. We first contacted the heads and administrative staff of the following clinical societies requesting to survey their membership: the African Organisation for Research and Training in Cancer (AORTIC), the Pan-African Women's Association of Surgeons (PAWAS), the AIDS Clinical Trials Group (ACTG), the Southern African HIV Clinicians’ Society, the South African Society of Obstetricians and Gynaecologists (SASOG), and the Democratic Nursing Organisation of South Africa (DENOSA). The secretariats of the societies subsequently circulated our online survey link to their members via email or through a listing in their newsletter(s). We also purposively sent the survey link to colleagues known to work in SRH-focused NGOs or clinical practices in Sub-Saharan Africa.

Respondents provided written consent to participation by clicking a ‘consent’ button within the first page of the survey after reading a description of the contents and planned usage of the data. The survey questions then included: the names and types of health facilities where s/he worked, whether s/he could refer for breast care services, breast care services available at places of work and referral sites, staff types working in breast care services at places of work and referral sites, and whether HIV care was integrated with breast care services. We also asked the respondents to provide their recommendations for improving the availability of breast care services in their respective countries.

Data management and analysis

We retrieved all responses from the online Survey Monkey platform by exporting them to Excel (Microsoft Corporation 2010). We then imported the dataset into Stata (version 14.0, StataCorp, College Station, Texas, USA) for cleaning and analysis. We excluded survey responses where an individual clicked on the link but did not answer any of the questions. We also excluded responses from individuals who reported only on sites outside of the Sub-Saharan African region.

Several facilities were listed more than once as a result of multiple respondents within countries. If the information provided on service availability or staffing at a facility differed across respondents, we reconciled the responses as follows. In cases where only 2 participants had different responses, we assumed the most ‘positive’ response. For example, if person A indicated the availability of an oncologist and person B indicated no availability of an oncologist, we coded the facility as having an oncologist. When there were more than 2 participants with different responses, we used the majority response.

We calculated simple proportions for categorical variables, stratifying by region, to present descriptive information regarding the survey respondents. Proportions represent non-missing responses. We then transposed the database to allow for description of service and staffing availability by facility and by region. We also worked with a graphic designer to create maps of Sub-Saharan Africa depicting the availability of breast care services by category in facilities as reported by respondents.

Finally, we analysed responses to open-ended questions using a thematic analysis approach in Excel (2010). Two coders reviewed and agreed on the outcomes for all coding.

This study was approved by the Human Research Ethics Committee (Medical) of the University of Witwatersrand (protocol Wits HREC M130368).

RESULTS

We estimate that the combined membership of the societies which participated in the survey was approximately 800 individuals at the time of surveying. The actual number of individuals is unknown due to confidentiality rules regarding the societies’ membership lists. In total, 99 individuals, representing 23 Sub-Saharan African countries responded to the survey. An additional 2 respondents who did not work in Sub-Saharan Africa responded but were excluded for ineligibility.

Respondent characteristics

Table 1 provides a summary of the eligible respondents’ locations and qualifications. Almost one in five respondents (19.2% (19/99)) were from South Africa due to our intentional focus on the country. Most respondents overall (80%) were medically trained; 9% had a nursing qualification; and the rest (11%) had other clinical or academic qualifications. Almost all respondents could offer or refer for breast care services: 88.9% had breast care services at their places of work, and an additional 8% could refer patients to other facilities for breast care services.

Table 1. Respondents' locations, qualifications, and access to breast care services (N=99) (n (%))

	Sub-Saharan African (excl. South African) respondents n=80	South African respondents n=19	All respondents N=99
Work environment^a			
Clinical setting	45 (60.0)	13 (76.5)	58 (63.0)
Academic setting	18 (24.0)	1 (5.9)	19 (20.7)
Academic and clinical settings	9 (12.0)	0 (0.0)	9 (9.8)
NGO and other	3 (4.0)	3 (17.6)	6 (6.5)
Qualification^b			
Medical	66 (84.6)	10 (58.8)	76 (80.0)
Nursing	3 (3.8)	6 (35.3)	9 (9.5)
Other clinical	1 (1.3)	0 (0.0)	1 (1.1)
Other academic	6 (7.7)	1 (5.9)	7 (7.4)
Other	2 (2.6)	0 (0.0)	2 (2.1)
Sub-qualification^c	(n=78)	(n=17)	(N=95)
General, internal medicine	47 (71.2)	4 (40.0)	51 (67.1)
Obstetrics and gynaecology	1 (1.5)	2 (20.0)	3 (3.9)
Surgery	3 (4.5)	2 (20.0)	5 (6.6)
Oncology / Surgical oncology	5 (7.6)	0 (0.0)	5 (6.6)
Pathology	6 (9.1)	1 (10.0)	7 (9.2)
Physiology	0 (0.0)	1 (10.0)	1 (1.3)
Radiation	1 (1.5)	0 (0.0)	1 (1.3)
Psychology	2 (3.0)	0 (0.0)	2 (2.7)
Radiation and Psychology	1 (1.5)	0 (0.0)	1 (1.3)
Works in facility that offers breast care services of any kind^d	73 (91.3)	15 (78.9)	88 (88.9)
Can refer women for breast care services	49 (77.8)	11 (78.6)	60 (77.9)*

^a Missing 7, ^b Missing 4, ^c Missing 19, ^d Missing 39

*Included in this group of 60 were 8 individuals who could not access services at their place(s) of work.

Staffing and service availability

The 99 respondents listed 180 unique health care facilities where they worked or could refer patients. Of the 180 facilities, 20.6% (37/180) were located in South Africa. Table 2 provides information on the services and staffing available at all facilities. The respondents indicated that just over one-third of the facilities had staff capable of performing advanced surgery, including cancer surgeons and reconstructive surgeons. The respondents also reported low availability of radiation and medical oncologists, psychologists, and counsellors capable of discussing breast disease.

Regarding the services offered at the facilities, clinical breast exams were reportedly available at roughly 80% of facilities in Sub-Saharan, including in South Africa. More

facilities reportedly had mammography than ultrasound services at 62.8% and 52.2% respectively. The availability of services to perform basic pathological assessment, defined as core biopsies, fine needle aspiration, and hormone receptor analysis, was variable, though 72.8% of all facilities had at least one kind of assessment available. Advanced breast assessments, which included stereotactic biopsies, HER2 (human epidermal growth factor receptor 2) determination and sentinel lymph node biopsy, were available at just over half of facilities. The respondents reported reasonable availability of surgery compared to advanced surgery, which included breast reconstruction, microdocheotomy, and wide local excision/lumpectomy. Treatment services (either chemotherapy or radiation) were available at 52.2% of all facilities, though in South Africa the proportion was lower at 40.5%.

Table 2. Staff and service availability at facilities where survey respondents work or refer patients for care (N=180) (n (%))

	Sub-Saharan African (excl. South African) facilities n=143	South African facilities n=37	All facilities N=180
Staff employed at facilities			
Cancer surgeon ^a	48 (43.2)	9 (40.9)	57 (52.9)
Specialist general surgeon ^b	87 (79.8)	14 (63.6)	101 (77.1)
Doctors capable of surgery ^a	95 (86.4)	17 (73.9)	112 (84.2)
Reconstructive surgeon ^c	44 (40.4)	9 (42.9)	53 (40.8)
Radiologist ^d	88 (80.7)	16 (69.6)	104 (78.8)
Pathologist ^c	78 (72.2)	11 (50.0)	89 (68.5)
Laboratory technician/technologist/ laboratory scientists ^a	95 (85.6)	13 (59.1)	108 (81.2)
Medical oncologist (subspecialist) ^b	59 (54.1)	9 (40.9)	68 (51.9)
Doctors trained in chemotherapy ^b	83 (76.9)	12 (52.2)	95 (72.5)
Radiation oncologist ^a	56 (50.5)	7 (31.8)	63 (47.4)
Psychologist ^c	52 (47.7)	9 (42.9)	61 (46.9)
Counsellor ^c	69 (63.3)	10 (47.6)	79 (60.8)
None of the above ^e	3 (6.8)	5 (50.0)	8 (14.8)
Services available			
Education on self-breast examination	95 (66.4)	28 (75.7)	123 (68.3)
<i>Exams</i>			
Physical (breast) examinations	114 (79.7)	31 (83.8)	145 (80.6)
<i>Imaging</i>			
Mammograms	77 (53.8)	17 (45.9)	94 (52.2)
Ultrasound/sonar	96 (67.1)	17 (45.9)	113 (62.8)
Any imaging service	102 (71.3)	20 (54.1)	122 (67.8)
<i>Basic pathological assessment</i>			
Core biopsy, routinely unguided	79 (55.2)	13 (35.1)	92 (51.1)
Core-biopsy, ultrasound guided	57 (39.9)	14 (37.8)	71 (39.4)
Fine Needle Aspiration	83 (58.0)	26 (70.3)	109 (60.6)

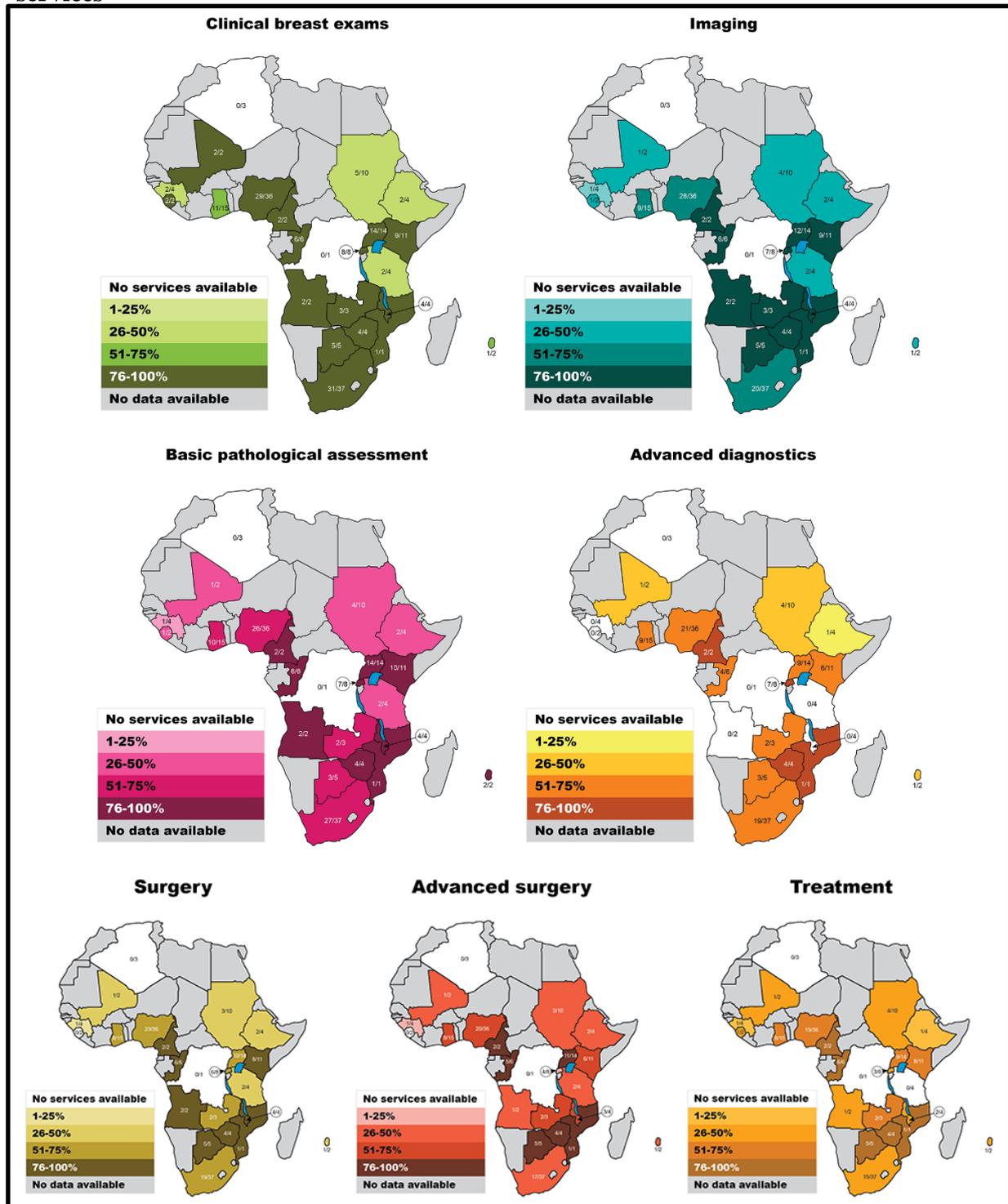
Hormone receptor analysis	62 (43.4)	20 (54.1)	82 (45.6)
Any basic pathological assessment service	104 (72.7)	27 (73.0)	131 (72.8)
<i>Advanced breast assessment</i>			
Stereotactic biopsies	22 (15.4)	11 (29.7)	33 (18.3)
HER2 determination	47 (32.9)	17 (45.9)	64 (35.6)
Sentinel lymph node biopsy	46 (32.2)	16 (43.2)	62 (34.4)
Any advance breast assessment service	75 (52.4)	19 (51.4)	94 (52.2)
<i>Surgery</i>			
Benign excision/surgical biopsy	90 (62.9)	19 (51.4)	109 (60.6)
Mastectomy	86 (60.1)	18 (48.6)	104 (57.8)
Any basic surgery service	91 (36.6)	19 (51.4)	110 (61.1)
<i>Advanced surgery</i>			
Breast reconstruction	41 (28.7)	13 (35.1)	69 (38.3)
Microdochectomy	29 (20.3)	12 (32.4)	41 (22.8)
Wide Local Excision/Lumpectomy	78 (54.5)	16 (43.2)	94 (52.2)
Any advanced breast surgery service	82 (57.3)	17 (45.9)	99 (55.0)
<i>Treatment</i>			
Chemotherapy	75 (52.4)	15 (40.5)	90 (50.0)
Radiation	50 (35.0)	11 (29.7)	61 (33.9)
Any treatment service	79 (55.2)	15 (40.5)	94 (52.2)

^a Missing 47, ^b Missing 49, ^c Missing 50, ^d Missing 48, ^e Missing 126

Figure 1 visually illustrates the availability of services by country. The maps within the figure should be interpreted carefully as the colour/shading represents the proportion of facilities that offered the service. If just one respondent listed one facility in the country, the result for the country depends entirely on that one respondent's report. Nonetheless, the maps give a basic idea of the availability or non-availability of services in the country. Clinical breast exams and imaging – both required for early identification of a lump or other breast issue, were reportedly available in all of the countries represented in the survey except for Algeria and the Democratic Republic of Congo (DRC). In fact, the respondents from Algeria and the DRC reported no availability of any breast care services (i.e. across all service types).

Basic pathological assessments and advanced diagnostics were less often available than the early identification services (i.e. breast exams and imaging). Interestingly, the respondents reported reasonable availability of diagnostic surgery and adjuvant treatment despite reports of low staffing levels in these areas.

Figure 1. Country-by-country proportions of survey facilities offering breast care services



Numbers within countries denote the numerator (which indicates that s/he said, yes, the service is available) and denominator (the number of total respondents) from each country.

Imaging = mammography or ultrasound services; Basic pathological assessment = Core biopsy, routinely unguided or Core-biopsy, ultrasound guided or Fine Needle Aspiration or Hormone receptor analysis; Advanced diagnostics = Stereotactic biopsies or HER2 determination or Sentinel lymph node biopsy; Surgery = Benign excision/surgical biopsy or Mastectomy; Advanced surgery = Breast reconstruction or Microdochectomy or Wide Local Excision/Lumpectomy; Treatment = Chemotherapy or Radiation

HIV integration

Two thirds of the respondents reported ‘integrated’ breast care and HIV services at their places of work, though the integration model differed (Table 3). In some facilities HIV services were offered by the same staff who offered breast care services. In other facilities, HIV services were offered by different staff, but in the same ward/clinic/rooms as the breast care services.

Table 3. HIV and breast care service integration at places of work as reported by survey respondents (N=99) (n (%))

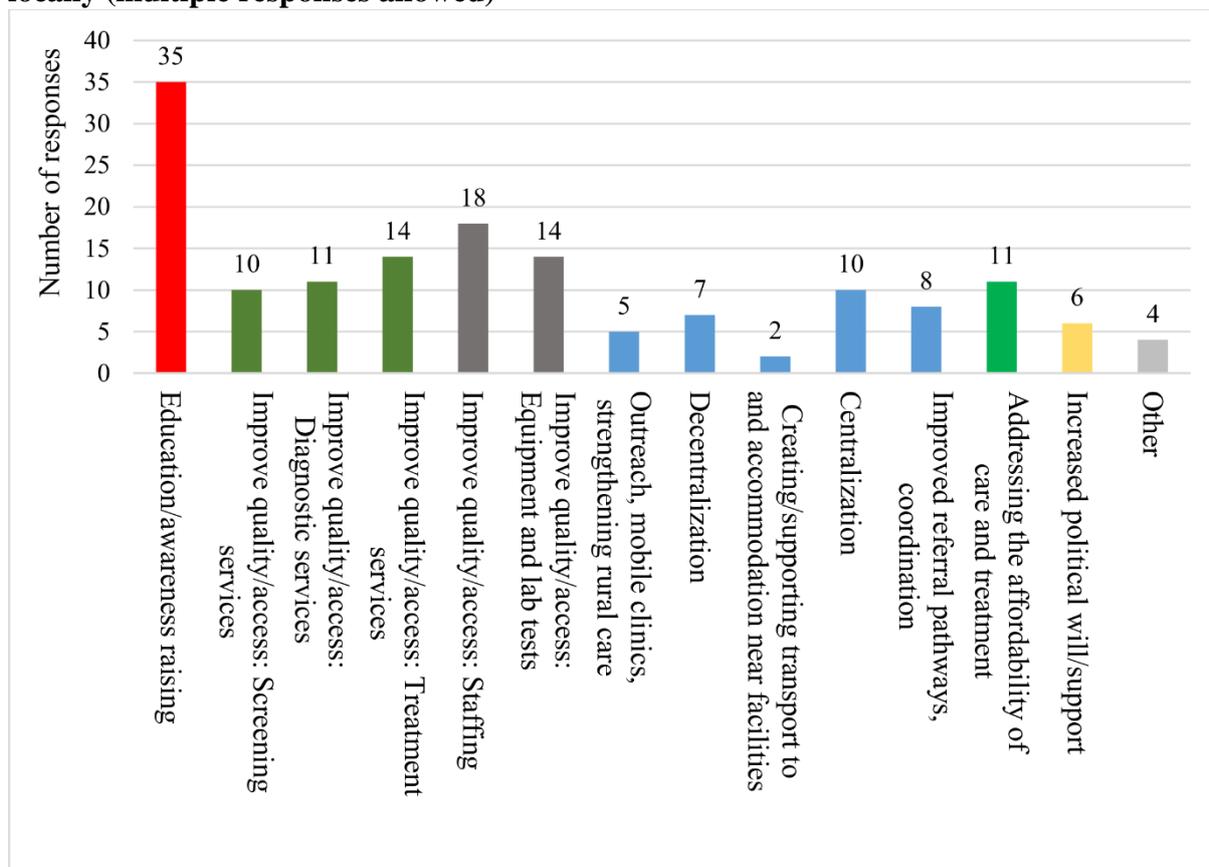
	All respondents N=99
Do the facilities where you work offer HIV-related services to breast care patients?^a	
Yes, HIV services are offered by the same staff who offer breast care services.	18 (22.2 %)
Yes, HIV services are offered by different staff, but in the same Ward/clinic/rooms as the breast care services.	17 (21.0%)
Yes, HIV services are offered in a different location and by different staff in the facility.	36 (44.4%)
No, There are no HIV services available at the facility.	9 (11.1%)
Not applicable, no breast care services at the facility.	1 (1.2 %)

^a Missing 18

Recommendations for improving breast care service availability

Just 59 (59.6%) of the 99 respondents provided recommendations for improving breast care services in their country. However, most of those respondents provided more than one suggestion – resulting in 155 suggestions overall. More than one in five of the suggestions (22.6% (35/155)) focused on public education and awareness raising efforts as a way of improving breast care service outcomes (Figure 2). Another roughly one in five of the suggestions involved targeting specific diagnostic or treatment services to improve the quality and/or availability. General recommendations to improve the availability and/or quality of specific resources (staff, equipment, and laboratory services) were also common.

Figure 2. Respondents' (n=59) recommendations for improving breast care services locally (multiple responses allowed)



Some of the recommendations were conflicting when comparing across and within countries. Some respondents called for improved geographic access via outreach programs, including mobile clinics; whereas others recommended improved transportation to and affordable accommodation near existing services. Similarly, some respondents called for reorganization of service delivery, recommending decentralization, while others recommended centralization as a way to improve treatment outcomes. The conflicting viewpoints are illustrated by the following quotes:

'In order to improve equitable access to oncology services, there is need to decentralize these services across the country.' – Cancer advocate, Zambia

'A centralized, well-resourced, open access service with transport facilitated from rural areas.' – Medical doctor, South Africa

Recommendations for improving referral pathways and coordination of care were also common. Finally, there were recommendations for addressing the affordability of breast care

and treatment and increasing overall political will and support for increasing access to quality services.

DISCUSSION

The individuals who responded to our online survey were selected based on their participation in regional and national clinical societies or their relationships with this study team, which consisted of HIV and breast care providers and epidemiological researchers. The responses suggest moderate and in some cases good availability of breast care services in their respective countries. Considering service availability by facility, clinical breast exams were reportedly available in roughly 80.6% of the facilities where the respondents worked or could refer patients. Imaging services and basic surgery were available in roughly 67.8% and 72.8% of facilities respectively. The respondents also reported moderate but lower availability of advanced diagnostics (52.2%), advanced surgery (55.0%), and cancer specialists – in radiation (47.4%) and surgery (52.9%). Treatment was also available in just 52.2% of facilities.

It is important to not over-interpret the input of individuals who were likely based in capital cities and other urban areas as representative of access throughout the countries represented, and importantly – even among respondents who might be more likely to work in or know of facilities offering breast care services – no staffing or service type was universally available. Another recent review of service availability in Sub-Saharan Africa painted a similar picture – i.e. of moderate availability of services with some exceptions^[12] – and highlighted that availability in some settings does not mean equitable access to quality services for all who need care.

Prior research has shown that reduced delays between breast cancer diagnosis and treatment initiation result in improved survival outcomes.^[13–15] To achieve optimal movement through the various stages of disease diagnosis and treatment, services must be well integrated – either in one location or via strong referral systems.

For breast cancer patients, timely access to cancer-specific services is essential. For women with breast concerns generally – including those with benign and malignant breast disease, integration with other health care services offers an opportunity for holistic management and reducing the burden of multiple visits. For areas with high HIV prevalence – such as Sub-Saharan Africa, integration with HIV services may also reduce visit-related fatigue and improve patient management. In this study, HIV and breast care services were reportedly both available at 87.6% of the facilities noted as places of work (among

respondents who answered the survey question. However, the model of offering HIV-related services differed. HIV and breast care services were offered by the same staff in just 22.2% of places of work.

There were several limitations to this study. The response rate was low due to the online, self-administered approach, and the number of respondents from each country was also limited. As noted above, the survey was also potentially subject to selection bias – and overstating access to services – as our respondents represented clinically trained individuals based in environments with tertiary facilities. That said, our survey is one of few to document service availability in this environment. Finally, we did not specifically ask about breast care services offered to men. Our assumption was that the reports of service availability represented services for women and men if needed.

CONCLUSIONS

Our findings suggest that access to the full continuum of breast care diagnostic and treatment services is rare in the countries represented in the survey. Improved access to a range of breast care services generally could improve timely and efficient management of patients and their health outcomes. The survey respondents highlighted the importance of educating the population regarding breast health. They also stated that breast care must be affordable and that for any advances to be made in terms of patient survival, political will is required.

Including breast care services as part of discussion and advocacy on sexual and reproductive health care could create further opportunities to address awareness of breast health, including how and where to access care when needed. Improved integration with HIV services would acknowledge the comprehensive health care needs of HIV-positive individuals – men and women alike – and provide opportunities to educate and test more individuals as they interact with the health service.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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