



Supporting Kenyan women with advanced breast cancer through a network and assessing their needs and quality of life

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Abstract

Introduction Metastatic breast cancer (MBC) patients have several unmet needs. The needs and quality of life of MBC women living in sub-Saharan Africa (SSA) are understudied. Facilitating the interaction of various caregivers is beneficial in addressing the needs. Internet-based resources play an important role in reaching out to these patients. We aimed to bring the various stakeholders into a joint network force, create a web-based portal, understand the needs of MBC patients, and assess the utilization of web-based resources for women from Kenya.

Methods A network of various stakeholders considered crucial in the care of Kenyan women with MBC was created. We conducted educational camps and assessed their needs, quality of life (QoL), and knowledge. We assessed the impact of utilizing web-based resources by MBC patients from here.

Results We formed a network involving partners and launched the first dedicated website for MBC from Kenya. The website has received 13,944 visits and 310,379 hits in 2 years. One hundred fourteen women living with MBC were interviewed, and our findings show that psychological needs (63%), physical support needs (60%), and health care system needs (55%) are leading areas of needs that increase with rural residence ($p=0.001$), less education ($p=0.003$), and aggressive treatments ($p=0.008$). Quality of life (QoL) confirmed better scores with urban residence ($p=0.002$), internet access ($p=0.010$), and stable disease ($p=0.042$).

Conclusions Creating a network of caregivers provides opportunities for cohesive efforts in understanding the psychosocial and medical needs of patients with MBC. Internet-based resources are an effective way of reaching out to them. Kenyan patients show extremely good uptake of internet-based resources.

Keywords Breast cancer support · Metastatic · Kenya · Web support · Breast advocacy

Introduction

Breast cancer (BC) is the most common cancer in Kenya with approximately 6,000 new cases per year [1]. The majority of BCs in Kenya present at an advanced stage [2, 3]. In

addition, 30% of women diagnosed with early breast cancer eventually develop metastatic disease [4]. Metastatic breast cancer (MBC) therefore comprises a significant population of women living with breast cancer. Patients living with MBC are recognized to be a special group with unique

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unmet needs [5]. The specific needs and quality of life (QoL) issues, for patients with MBC in sub-Saharan Africa (SSA), have especially been neglected. There has been very little effort on utilizing internet-based platforms for helping women with MBC from here, whereas there is known to be an effective modality [6]. Internet penetration of up to 43% among the Kenyan population provides a good opportunity to explore the utilization of this strategy [7]. To identify and address the gaps in needs and QoL of MBC patients, we aimed to develop a nationwide network of physicians, health care advocates, governmental and non-governmental organizations, faith-based groups, psychologists, nursing advocates, support groups, and social organizations to come together to identify the needs and improve QoL of MBC patients in Kenya. Supported by the Union for International Cancer Control (UICC), we conducted seminars and sessions for patients with MBC in multiple cities within the Republic of Kenya, in an attempt to educate them, engage them, learn from them, and have open discussions about their needs, QoL, and knowledge of breast cancer. We launched an interactive website dedicated to women with MBC in Kenya, called the Kenya Metastatic Breast Cancer Network (www.kmbcn.org). The first of its kind support tool for women with MBC from here. We present our experience of developing a web-based platform and findings from our interactions with Kenyan women living with MBC and the results of the needs assessment, QoL, and level of knowledge surveys from these interactions. We also present the uptake and utilization of internet-based resources in this population.

Methods

Setting up Kenya Metastatic Breast Cancer Network

Led by the principal investigator (PI) at the Aga Khan University Hospital, Nairobi (AKUHN), we initiated contacts with all stakeholders involved in the care of breast cancer patients including private and government partners. The stakeholders as described above established the Kenya Metastatic Breast Cancer Network (KMBCN). Supported by a grant from the Union of International Cancer Control (UICC) [8], the major goal of KMBCN was to recognize this marginalized community of breast cancer, reach out to them physically and virtually, identify their needs, and attempt to improve their QoL in urban and rural Kenya.

It was recognized that efforts would need to be made to reach out to these women proactively. The stakeholder group met several times at AKUHN to brainstorm an approach to reach out to these women. It was recognized that physical and virtual platforms would be used to identify their needs, assess their QoL, assess their knowledge about their disease,

and hold educational sessions to provide first-hand information that they need.

Developing a website

Developing a virtual online interactive support forum was central to this endeavor [8], through which MBC patients and their caregivers could access information on social, psychological, spiritual, religious, and clinical needs. The online platform further allowed these women opportunities to interact with various support providers, remain abreast with support and educational activities, and know about the latest updates in the country on MBC. An online website called <http://www.kmbcn.org>, representing the KMBCN, was launched in August 2018 in Nairobi. The website content was intended to be culturally sensitive and customized for Kenyan women with MBC and their caregivers. A core team responsible for overseeing the professional and technical content for the website was formed and led by the PI, grant recipient of the UICC SPARC project. The website is fully interactive and has the capability for calendar integration to link events. Links to local, regional medical facilities with map directions, and for spiritual, psychological, religious, and other support groups were provided. Links to useful internet resources such as guidelines for patients and global support groups were provided as well. The website content also included the latest news, upcoming events, and trending topics, announcements, publications insights, reflections, and patient stories. The registration and information aspect of the website allows users to create their profiles, interact with caregivers about their concerns, and ask questions. Caregivers from various cadres were identified as champions of updating the information on the website and responding to questions posed by users. Endorsements were sought from major stakeholders including the National Cancer Institute of Kenya, Ministry of Health, and Kenya Society of Hematology and Oncology (KESHO). Pamphlets on basic MBC awareness with links to the website were distributed to major hospitals and various points of health care delivery including county, district, and local hospitals. Social media links were created and linked to the website. Following the launch, the PI and other team members visited all the participating sites to create awareness of the website among health workers and provide hands-on training on functionalities and navigation of the website. Technical management teams monitored the website to maintain security, the legality of the content, the authenticity of the users, privacy, prevention of piracy, and spam content.

The website is continuously updated and modified to remain current and reflect local concerns. The overall activity of the website is supervised, moderated, and monitored by the PI with the assistance of the core group assigned this task.

Understanding the needs, QoL, and knowledge

From July 2018 to July 2019, we held five educational camps for women with MBC. Supported by our partners in this endeavor, we held sessions in the cities of Mombasa, Eldoret, and Nairobi. During the awareness sessions, team members from KMBCN made presentations on various aspects of breast cancer, from the role of screening to treatment with a focus on the need of understanding the value of integrated care. During these meetings, one-to-one interviews and surveys were conducted on women with single inclusion criteria of living with metastatic breast cancer and having a European Cooperative Oncology Group (ECOG) performance status of 0–2, to assess their needs, QoL, and knowledge. After seeking appropriate approvals, for needs assessment, we used the Supportive Care Needs Survey short format (SCNS-SF34) [9], for QoL we used the Functional Assessment of Cancer Therapy–Breast Cancer (FACT-B) validated instrument [10], and we used an internally developed previously validated BC Knowledge assessment tool from the Aga Khan University (AKU) [11] to assess the knowledge of breast cancer. The surveys were administered on paper, and the data was then entered electronically.

Statistical methods

For analyzing the quantitative data on the assessment of needs, QoL, and knowledge of BC, categorical data were presented as frequencies and percentages, whereas continuous data were presented as median and interquartile ranges. Univariate analysis was conducted using Fisher's exact test for categorical data and a non-parametric test (Mann–Whitney test) for continuous data. Pairwise comparisons where there were more than 2 groups were also conducted. Spearman's correlations were used to identify the bivariate correlations among the needs and FACTB surveys. A p -value of <0.05 was considered statistically significant.

Website data

The data on the assessment of website utilization was collected through AWStats. AWStats is an open-source Web analytics-reporting tool, suitable for analyzing data from internet services such as web, streaming media, mail, and FTP servers.

Ethical approvals

The study was conducted in compliance with ethical principles adapted through and under the declaration of accordance of Helsinki. Complete confidentiality was observed, and interviews were conducted following written informed consent. Formal ethical approvals were obtained from the

Institutional Ethics Review Committee (IERC) at AKUHN and National Commission for Science, Technology, and Innovation (NACOSTI), Ministry of Education, Kenya.

Results

KMBCN activities

The study team members who participated and formed the core group met every 2 months and provided input on the content of the website. A professional website developer worked closely with the core group, activities were relayed to social media, and content development was jointly planned to keep in mind cultural sensitivities and a volunteer intern worked closely with the PI to collate all the content.

Assessment of needs, QoL, and knowledge

This study enrolled 114 patients. The mean age of the patients was 51.4 years ($SD = 12.7$), and 56.1% of the patients were married. The majority of the patients (92.9%) were of African ethnicity, and 90.2% were following Christianity. More than half (54.6%) resided in rural areas whereas only 23.7% had tertiary education.

Needs assessment

Analysis of 114 patients, as shown in Table 1, showed that 103 (90.4%) patients reported at least one “moderate to high” level unmet supportive care need and only 5 (4.4%) reported no needs. The top 10 items that patients reported a moderate to a high level of need for help with are also shown in Table 1. The most unmet needs concerning psychological issues (63%), needs around daily living and physical support (60.5%), and needs around health care systems (55.4%) are shown in Fig. 1. Univariate analysis on the needs assessment showed that psychological needs were highest among patients living in rural areas ($p = 0.001$), who were less educated ($p = 0.003$), with worsening disease ($p = 0.001$), and those who were on systemic chemotherapy ($p = 0.008$). Health Information needs were higher with advanced metastatic disease ($p = 0.017$), having the worsening disease ($p = 0.001$), and those receiving systemic chemotherapy ($p = 0.004$). Needs on daily living were highest in those living in rural areas ($p = 0.007$), less educated ($p = 0.009$), having no internet access ($p = 0.032$), and those with worsening disease ($p = 0.001$). The needs on sexuality were higher in married ($p = 0.001$) and pre-menopausal women ($p = 0.014$). The needs for patient care and support were higher with worsening disease ($p = 0.013$) (Tables 2 and 3).

Table 1 Prevalence of supportive care needs and the top ten “moderate or high” level unmet supportive care needs

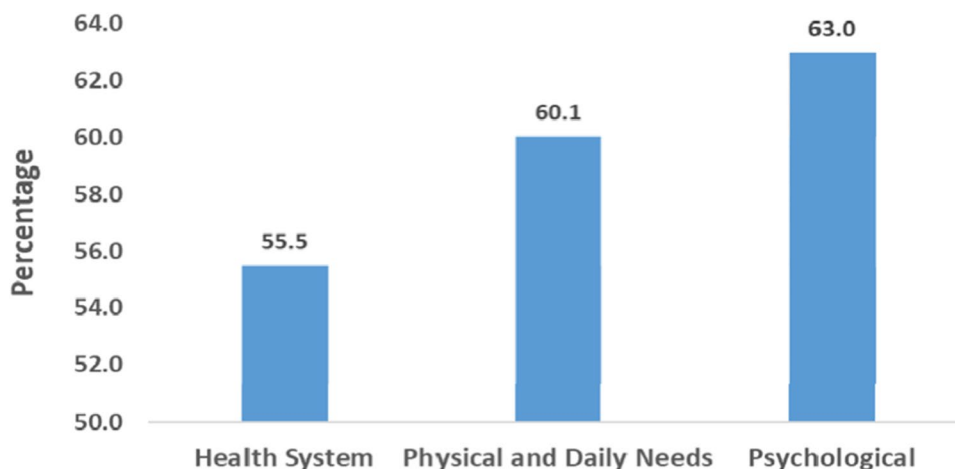
		Total (N= 114)	
No Needs ^a		5 (4.4%)	
Low Needs ^b		6 (5.3%)	
Moderate or High Needs ^c		103 (90.4%)	
Rank	SCNS-SF34 item	Number (%)	Domain
1	Not being able to do the things you used to do	73 (64.0)	Physical and daily needs
2	Fears about the cancer spreading	71 (62.3)	Psychological
3	Being given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home	68 (59.6)	Health system
4	Being given written information about the important aspects of your care	65 (57.0)	Health system
5	Work around the home	64 (56.1)	Physical and daily needs
6	Having access to professional counseling (e.g., psychologist, social worker, counselor, nurse specialist) if you, family or friends need it	62 (54.4)	Health system
7	Worry that the results of treatment are beyond your control	62 (54.4)	Psychological
8	Anxiety	61 (53.5)	Psychological
9	Being given explanations of those tests for which you would like explanations	58 (50.9)	Health system
10	Feelings of sadness	58 (50.9)	Psychological

^aSelected “no” need for help to all 34 items

^bSelected “low” level need for help to at least one item, but did not select “moderate”

^cSelected “moderate” or “high” level need for help to at least one item

Fig. 1 Proportion of the most prevalent “moderate or high” level unmet supportive care needs as per the domain



QoL assessment

Various FACT-B domains, where a higher score is better, showed that physical wellbeing (PWB) score was higher in patients living in urban areas ($p=0.002$) and with stable disease or improving disease ($p=0.001$). Emotional wellbeing (EWB) was higher in those that were single ($p=0.006$), living in urban residence ($p=0.004$), having internet access ($p=0.010$), with stable or improving disease status ($p=0.011$), and those on oral hormonal therapy ($p=0.001$). Functional wellbeing (FWB) scores

were higher with urban residence ($p=0.004$), with internet access ($p=0.010$), with limited, single-site metastasis ($p=0.039$), and with improving disease ($p=0.039$). The overall FACT-G was improved for those living in an urban area ($p=0.007$), having internet ($p=0.014$), single site of disease ($p=0.042$), and stable disease ($p=0.004$). On breast cancer-specific subscale (BCS), pre-menopausal women ($p=0.009$) and stable disease ($p=0.034$) scored higher. FACT-B total score was better with urban residence ($p=0.003$), having internet access ($p=0.032$), and having stable disease ($p=0.002$) (Table 4).

Table 2 Univariate analysis on the Needs assessment domains based on different demographic and clinical variables

Variables	Psychology			Health information			Daily living			Patient care			Sexuality		
	Median	Range	p value	Median	Range	p value	Median	Range	p value	Median	Range	p value	Median	Range	p value
<i>Gender</i> (n = 110)															
Female (n = 106)	34	(26, 40)	0.430	35	(28, 42)	0.097	17	(13, 21)	0.198	13	(10, 16)	0.489	6	(3, 8)	0.908
Male (n = 4)	33	(25.5, 38)		30	(25.5, 31.5)		13	(10.5, 15.5)		13.5	(10.5, 15)		5	(4, 6)	
<i>Married</i> (n = 106)															
Single (n = 14)	29	(20, 39)	0.141	31.5	(22, 40)	0.690	11.5	(7, 22)	0.167	12.5	(10, 16)	0.509	5	(3, 7)	0.001
Married (n = 62)	34	(25, 39)		35	(27, 42)		17	(11, 20)		13	(10, 16)		6	(4, 8)	M vs O < 0.001
Others (n = 30)	37.5	(31, 41)		34.5	(31, 38)		17	(16, 19)		15	(12, 16)		3	(3, 5)	
<i>Residence</i> (n = 106)															
Rural (n = 57)	37	(30, 43)	0.001	35	(31, 41)	0.340	18	(16, 21)	0.007	14	(12, 16)	0.224	5	(3, 7)	0.392
Urban (n = 49)	30	(20, 37)		34	(24, 40)		16	(10, 19)		13	(10, 16)		6	(3, 7)	
<i>Education</i> (n = 102)															
Primary (n = 39)	36	(30, 41)	0.003	34	(30, 38)	0.122	17	(15, 21)	0.009	13	(11, 15)	0.830	3	(3, 6)	0.027
Secondary (n = 38)	34.5	(23, 42)	P vs T 0.002	37.5	(24, 45)		17	(13, 22)	P vs T 0.016	14	(10, 17)		6	(3, 8)	P vs S 0.025
Tertiary (n = 25)	25	(20, 37)	S vs T 0.034	29	(22, 40)		14	(9, 20)	S vs T 0.022	13	(10, 18)		6	(4, 8)	
<i>Occupation</i> (n = 110)															
Employed (n = 41)	32	(23, 39)	0.513	35	(25, 41)	0.653	17	(11, 21)	0.610	12	(10, 16)	0.564	6	(3, 8)	0.074
Not employed (n = 69)	35	(30, 40)		35	(30, 41)		17	(15, 20)		15	(10, 16)		5	(3, 7)	
<i>Pre meno-pause</i> (n = 105)															
Yes (n = 36)	33	(24, 38.5)	0.421	36	(28.5, 41.5)	0.741	17	(10.5, 21)	0.900	14	(10, 16)	0.962	6	(4, 9)	0.014
No (n = 69)	35	(28, 41)		35	(29, 42)		17	(14, 20)		14	(10, 16)		4	(3, 7)	
<i>Internet</i> (n = 102)															
Yes (n = 52)	32	(22, 40)	0.281	35	(28, 40)	0.377	17	(10, 20)	0.032	13	(10, 16)	0.471	6	(3, 7)	0.517
No (n = 47)	35.5	(30, 40.5)		37	(32, 44)		19	(15, 22)		15	(12, 16)		5	(3, 7)	
<i>Site</i> (n = 99)															
Multiple (n = 52)	32.5	(27, 39.5)	0.296	34.5	(27.5, 42.5)	0.017	17	(15, 21)	0.319	15	(10, 16)	0.874	5.5	(3, 7)	0.891
Single (n = 47)	36	(29, 40)		34	(26, 38)		16	(11, 20)		13	(10, 15)		5	(3, 7)	
<i>Current status</i> (n = 99)															
Stable (n = 31)	30	(20, 38)	0.001	30	(22, 41)	0.001	17	(12, 20)	0.001	11	(10, 15)	0.013	6	(4, 8)	0.043
Improving (n = 57)	36	(30, 40)	S vs W 0.001	33	(27, 37)	S vs W 0.001	17	(13, 19)	S vs W 0.001	14	(12, 15)	S vs W 0.010	4	(3, 7)	S vs I 0.024
Worsening (n = 11)	43	(32, 45)	I vs W 0.049	44	(37, 54)	I vs W 0.001	22	(20, 24)	I vs W 0.005	16	(13, 25)		7	(3, 9)	

Table 2 (continued)

Variables	Psychology		Health information		Daily living		Patient care		Sexuality	
	Median	Range	Median	Range	Median	Range	Median	Range	Median	Range
<i>Treatment</i> (<i>n</i> =93)	30	(21, 36)	33	(25, 37)	17	(10, 19)	13	(10, 15)	6	(3, 7)
<i>Oral/</i> <i>Hormonal</i> (<i>n</i> =33)										
<i>Systematic</i> (<i>n</i> =60)	36.5	(31, 41)	35	(30, 41)	17	(15, 20.5)	15	(10.5, 16)	5	(3, 7.5)
<i>Life expect-</i> <i>tancy</i> (<i>n</i> =97)	43	(37, 45)	44	(41, 46)	22	(21, 25)	16	(16, 19)	3	(3, 6)
<i><6 Months</i> (<i>n</i> =88)	33.5	(27.5, 39)	33.5	(25, 38)	17	(13, 19)	13	(10, 15)	5	(3, 7)

Needs and QoL assessment

Individual domains based on the needs and FACT-B assessment were negatively correlated. As shown in Table 5, FACT-G, FACT-B Total, and FACT-B TOI were negatively correlated with psychological needs, health information needs, daily living needs, and patient care needs. As the FACT-B scores increased the needs on the particular domain decreased ($p < 0.001$). The overall correlations are presented in Supplementary 1.

Knowledge assessment

Based on the knowledge assessment, 42% were knowledgeable about the clinical features of breast cancer. Furthermore, 36% knew the breast cancer pathology, 61% claimed to know what treatment they were receiving, and 24% knew the type of breast cancer they were diagnosed with. Awareness of different terms, 54% were familiar with the term metastatic breast cancer, 10% were familiar with triple-negative breast cancer, and 13% were familiar with HER2 breast cancer. Only 24% reported having received some written information about their cancer and 84% desired to have a written summary about their disease status. The overall knowledge assessment summary is presented in Supplementary 2.

Assessment of website data

The website received 46,571 hits and 5,099 visits from August 2018 to Dec 2018. It received 223,266 hits and 7,561 visits from January 2019 to December 2019 and 40,542 hits and 5,099 visits from January 2020 to September 2020. Overall in 2 years, the website has received 7,864 unique visitors defined as the number of unduplicated visitors to the website, 13,944 visits defined as the session that visitors spent on the site, and 379,861 hits defined as the number of interactions with the website that results in data being sent to analytics.

Discussion

Women with MBC are a special group of women with BC with unique needs which evolve over the period [12]. Improved diagnosis and treatment have resulted in a growing number of women living with MBC [13]. While undergoing different treatment modalities over time, these patients not only go through clinical phases of treatment but also through social and psychological phases of dealing with what is an ultimately incurable disease. While research has largely focused on efforts to improve survival, less attention has been paid to the needs and QoL of patients living with MBC [14]. The sub-Saharan African MBC population seems

Table 3 Univariate analysis on the FACT-B domains based on different demographic and clinical variables

Variables	PWB			SWB			EWB			FWB			FACT-G			BCS			FACT_B_TOTAL			FACT_B_TOI			
	Median	Range	p value	Median	Range	p value	Median	Range	p value	Median	Range	p value	Median	Range	p value	Median	Range	p value	Median	Range	p value	Median	Range	p value	
Gender																									
Female (n=85)	16	(8, 22)	0.231	21	(18, 67, 25, 67)	0.270	15	(9, 20)	0.393	15	(9, 20)	0.660	65	(47, 8, 78)	0.417	24, 44	(19, 27, 78)	0.100	88, 67	(69, 22, 108)	0.338	53, 44	(40, 67)	0.228	
Male (n=2)	25	(25, 25)		21, 58	(21, 22, 17)		17, 5	(16, 19)		18	(18, 18)		82, 08	(80, 84, 17)		31, 11	(27, 78, 34, 44)		113, 19	(111, 95, 114, 44)		74, 11	(70, 78, 77, 44)		
Married																									
Single (n=12)	18	(12, 27)	0.405	22, 5	(18, 92, 25, 5)	0.146	19	(13, 21, 5)	0.006	19	(8, 25)	0.803	66	(58, 42, 98)	0.202	26, 22	(19, 5, 28)	0.853	93	(78, 92, 126)	0.338	59	(44, 5, 79, 5)	0.683	
Married (n=49)	16	(8, 22)		22	(18, 67, 26, 83)		16	(12, 20)	S vs O 0.025	15	(10, 20)		68	(52, 17, 78)		25	(18, 89, 28)		91	(69, 5, 109)		55	(41, 67)		
Others																									
Others (n=21)	15	(7, 19)		19, 83	(18, 22, 17)		10	(6, 13)	M vs O 0.011	15	(13, 18)		57, 67	(43, 83, 71, 33)		24	(21, 11, 27)		76, 67	(64, 94, 98, 33)		53	(40, 66)		
Residence																									
Rural (n=42)	10	(6, 20)	0.002	21	(18, 67, 25, 67)	0.764	12, 5	(8, 16)	0.004	13, 5	(9, 17)	0.004	57, 83	(45, 71)	0.007	22	(16, 67, 26, 67)	0.001	83, 42	(64, 97)	0.003	48	(31, 61)	0.001	
Urban (n=42)	18	(11, 26)		21	(18, 25, 67)		18, 5	(12, 22)		17, 5	(13, 27)		69, 17	(56, 5, 97)		26	(24, 29)		96, 17	(76, 5, 125)		60, 5	(44, 78, 78)		
Education																									
Primary (n=81)	15	(8, 22)	0.324	21	(19, 83, 24, 5)	0.942	13	(10, 18)	0.291	15	(13, 17)	0.575	66, 83	(56, 74)	0.499	24, 44	(21, 27)	0.627	91	(72, 100, 67)	0.318	55	(40, 78, 64)	0.482	
Secondary (n=34)	14	(6, 23)		21, 58	(17, 5, 25, 67)		16	(8, 20)		14, 5	(9, 24)		60, 75	(45, 33, 87, 33)		24, 5	(19, 27, 78)		84, 25	(64, 114)		53, 5	(34, 33, 69)		
Tertiary (n=22)	18	(11, 25)		22, 75	(18, 26)		17	(11, 22)		17	(12, 25)		68, 67	(56, 83, 97)		25, 5	(19, 28)		93, 17	(80, 83, 121, 09)		57, 33	(47, 77)		
Occupation																									
Employed (n=85)	15, 5	(9, 5, 21)	0.812	21, 5	(18, 67, 25, 67)	0.340	15, 5	(11, 19, 6)	0.410	15	(9, 18)	0.232	66, 83	(51, 92, 75)	0.281	24, 72	(19, 27)	0.249	90, 5	(71, 08, 99, 5)	0.242	55	(42, 66)	0.275	
Not employed (n=45)	17	(8, 23)		21	(18, 67, 25, 67)		16	(8, 20)		15	(12, 25)		66, 83	(47, 87, 33)		25	(19, 28)		88	(69, 114)		54	(40, 73)		
Pre menopause																									
Yes (n=28)	17, 5	(9, 25)	0.422	21	(17, 75, 23, 33)	0.215	18	(11, 5, 21, 5)	0.140	15, 5	(11, 22)	0.883	68, 33	(51, 92, 85, 75)	0.552	27	(21, 5, 30)	0.009	93	(74, 114, 39)	0.325	55, 22	(45, 89, 75)	0.238	
No (n=52)	16	(8, 22)		22, 67	(18, 67, 26, 83)		14, 5	(9, 5, 19, 6)		15	(9, 20)		66, 83	(47, 78)		24	(17, 5, 26, 83)		88, 33	(69, 11, 105)		55	(38, 28, 66)		
Internet																									
Yes (n=40)	16, 5	(10, 25)	0.071	23, 17	(18, 33, 26, 42)	0.269	18	(12, 5, 20, 5)	0.010	17	(13, 25)	0.010	68, 67	(56, 25, 93)	0.014	24, 72	(18, 44, 28)	0.767	93, 06	(77, 33, 118, 54)	0.032	56	(42, 77, 5)	0.089	
No (n=37)	12	(7, 20)		21	(18, 67, 23, 33)		13	(8, 18)		13	(9, 17)		59, 83	(44, 17, 73, 67)		24	(20, 27)		87, 61	(64, 100, 67)		47	(37, 11, 64)		
Site																									
Multiple (n=74)	14	(7, 5, 20)	0.527	21	(15, 9, 23, 33)	0.138	13, 1	(8, 5, 19, 6)	0.052	13	(8, 5, 16, 5)	0.039	57, 25	(45, 17, 72, 5)	0.042	24, 22	(20, 27)	0.715	83, 47	(64, 42, 99, 5)	0.108	52, 5	(39, 5, 66)	0.294	
Single (n=34)	17	(9, 23)		21, 5	(18, 67, 26)		15	(9, 20)		17	(14, 25)		68, 88	(56, 83, 87)		25	(19, 28)		92, 31	(75, 83, 114, 44)		58	(42, 73)		
Current status																									
Stable (n=28)	18	(8, 25, 5)	0.001	22, 17	(17, 4, 25, 83)	0.302	18, 5	(9, 5, 20, 5)	0.014	16	(11, 5, 25)	0.036	69, 5	(48, 9, 92, 75)	0.002	24, 5	(19, 28)	0.039	96	(69, 11, 118, 29)	0.002	55	(41, 76, 44)	0.003	
Improving (n=36)	17	(11, 5, 20, 5)	S vs W 0.001	21	(18, 67, 25, 08)		13, 5	(10, 17)	S vs W 0.011	15	(12, 5, 19, 5)	S vs W 0.042	65, 33	(56, 25, 74)	S vs W 0.003	25	(22, 27)	I vs W 0.034	89, 33	(76, 17, 99, 5)	S vs W 0.003	56, 5	(45, 89, 66)	S vs W 0.007	
Worsening (n=10)	3, 5	(2, 7)	I vs W 0.002	19, 25	(17, 5, 21)		8	(4, 13, 2)		10	(9, 14)		44, 62	(36, 5, 52, 17)	I vs W 0.004	19, 5	(13, 33, 21, 11)		58, 87	(49, 5, 76, 67)	I vs W 0.004	33, 67	(26, 42)	I vs W 0.004	
Treatment																									
Oral/ Hormonal (n=69)	20, 5	(11, 25)	0.160	24, 25	(17, 5, 28)	0.483	19, 1	(14, 22)	0.001	17, 5	(13, 25)	0.077	73, 83	(50, 99)	0.059	25	(22, 28)	0.369	99, 33	(69, 8, 125)	0.050	62, 5	(44, 78)	0.103	
Systematic (n=43)	14	(8, 20)		21	(18, 67, 23, 33)		11	(8, 18)		14	(9, 17)		63, 5	(50, 69)		24	(19, 27)		86	(69, 95, 83)		52	(37, 56, 61, 44)		
Life Expectancy																									
≥6 Months (n=7)	3	(2, 6)	0.001	19, 83	(17, 5, 22, 17)	0.237	8	(4, 14)	0.024	10	(7, 13)	0.019	43, 33	(32, 67, 52, 17)	0.003	20	(16, 26)	0.162	62, 33	(48, 67, 78, 17)	0.007	31	(26, 42)	0.006	
<6 Months (n=72)	17	(9, 23)		21	(18, 67, 25, 67)		15	(10, 20)		15	(12, 20)		67	(53, 67, 80)		25	(20, 27)		91	(72, 111, 95)		55	(43, 5, 69)		

PWB physical wellbeing, SWB social wellbeing, EWB emotional wellbeing, FWB functional wellbeing, FACT-G Functional Assessment of Cancer-General, BCS breast cancer specific subscale

Table 4 Correlations between the Needs and FACT-B assessment

		FACT G	FACT B TOTAL	FACT B TOI	Psychology	Health Information	Daily Living	Patient Care	Sexuality
FACTG	ρ	1	.982**	.916**	-.673**	-.339**	-.672**	-.491**	0.129
	p value		<0.001	<0.001	<0.001	0.001	<0.001	<0.001	0.236
FACT B TOTAL	ρ		1	.955**	-.713**	-.361**	-.666**	-.528**	0.091
	p value			<0.001	<0.001	0.001	<0.001	<0.001	0.404
FACT B TOI	ρ			1	-.691**	-.395**	-.728**	-.545**	0.029
	p value				<0.001	<0.001	<0.001	<0.001	0.791
Psychology	ρ				1	.500**	.671**	.625**	-0.176
	p value					<0.001	<0.001	<0.001	0.105
Health Information	ρ					1	.480**	.673**	0.005
	p value						<0.001	<0.001	0.964
Daily Living	ρ						1	.483**	-0.061
	p value							<0.001	0.579
Patient Care	ρ							1	-0.096
	p value								0.379
Sexuality	ρ								1
	p value								

**Correlation is significant at the 0.01 level (2-tailed)

*Correlation is significant at the 0.05 level (2-tailed)

N= 86 for all pairwise correlations

to be especially neglected in this regard. Some attempts have been made to highlight inequities in the receipt of care and lack of education in the breast cancer population, but overall there are negligible publications on this subject from SSA [15]. One of the largest international patient-based surveys to study the needs and QoL of patients with MBC did attempt to include countries from low- and middle-income countries (LMICs), but SSA was still excluded from the study population [16]. Even from the standpoint of western research focus, the MBC population despite their unique challenges remains an understudied population, and most of their needs go unreported [16]. Studies from the western literature, however, support the notion that women living with MBC crave more information, prefer online as well as in-person information, seek selective information, have a high level of psychological distress, seek support, are interested in experiences of others, and rely on a strong family system for coping [17]. Emotional, physical, and psychological needs are known to be the major concern of early breast cancer survivors as well [18], and psychological needs have been shown to take precedence in MBC [19].

Our study, which is, perhaps the first from SSA to report on needs and QoL of patients with MBC, assessed by an instrument that has shown reliability, validity, and sensitivity and psychometric sensitivity in several populations

groups [10, 20], suggests that three most common needs in women living with MBC from here are psychological, physical assistance in daily living, and health care system needs. Advanced disease, rural residence, less education, and lack of internet access increases their needs. Quality of life is also better in women living in urban areas, having less burden of disease, being on non-chemotherapy treatment, having a postmenopausal status, and having access to the internet. We demonstrate that higher unmet needs are associated with a decrease in QoL. Most support groups and online resources designed for MBC patients are from the west; although the information available is for all, they certainly lack a local connection [21]. To the best of our knowledge, there is no dedicated web resource dedicated to women with MBC from SSA available, except the one we have launched. Realistic usage of internet-based resources has several determinants that constitute important factors in the success of web-based forums for cancer patients [22]. The internet-based forums are a new and unique way of providing support to women in an evolving health care setting, where support itself by any modality is new. We recognize that at this point, accessing the information from a web-based is a metric of success rather than data collection. Several best-known online international patient support resources are beginning to show their impact in terms of data collection and in supporting

Table 5 Knowledge assessment responses

		Frequency	Percentage
Knowledgeable about the clinical features of breast cancer (such as type of breast cancer, size, stage, lymph nodes)	Agree	44	42.3%
	Disagree	41	39.4%
	Neutral	19	18.3%
Knowledgeable about breast cancer pathology	Agree	38	36.5%
	Disagree	44	42.3%
	Neutral	22	21.2%
Knowledgeable about breast cancer treatment	Agree	66	61.1%
	Disagree	23	21.3%
	Neutral	19	17.6%
Do you know what type of breast cancer you were diagnosed with?	Yes	25	23.6%
	No	42	39.6%
	A little bit	39	36.8%
Aware of the term: metastatic breast cancer	Yes	56	53.8%
	No	48	46.2%
Aware of the term: triple negative breast cancer	Yes	10	9.7%
	No	93	90.3%
Aware of the term: HER 2 neu positive breast cancer	Yes	13	12.6%
	No	90	87.4%
Aware of the term: hormone positive breast cancer	Yes	14	13.6%
	No	89	86.4%
What was the stage of your breast cancer?	I	5	4.9%
	II	20	19.4%
	III	30	29.1%
	IV	48	46.6%
Did you have any positive lymph nodes?	Yes	39	54.2%
	No	33	45.8%
Have you ever received a written summary of your breast cancer diagnosis, clinical features, pathology, treatment?	Yes	26	23.9%
	No	83	76.1%
In general, how would you feel about receiving this type of personalized breast cancer summary?	I would like it	90	84.1%
	I don't need to know	3	2.8%
	I know, but I like more information	11	10.3%
	My doctor has given me all the information	3	2.8%

patient-centered cancer care delivery [23]. In this context, utilization of our website for data collection would be premature; however, visits should be a metric of success. We recognized an ardent longing for more knowledge and information around breast cancer in our women, during our several breast cancer awareness and diagnostic camps conducted and reported previously [11, 24]. Our findings are consistent with several studies that indicate rural residence is negatively associated with QoL, needs, and disease outcomes [25–27]. Our findings from Kenyan women are also consistent with what has been reported from the QoL indicators from other LMICs, which indicate that age, educational level, and status of disease affect QoL [28, 29]. We indicate that internet access is associated with a better QoL; this is an encouraging sign, as Kenya becomes increasingly digitalized [30] our initiative of a web-based forum would perhaps have

better uptake. Our website data utilization is an encouraging sign of greater acceptability of internet-based resources for Kenyan women. Approximately 14,000 visits to the website in just 2 years from establishment assert the internet friendliness of this country's population and call for further exploitation of this resource. Our physical contact sample was not broad which remains a study limitation; we assume that since we conducted the camps on one given day, attendance to the site for camp only had financial implications for the patients; therefore, physical sampling remained modest. A constant provider engagement on-site may provide a better uptake of assessment instruments. The IT-based solutions are a potentially powerful way of providing care to cancer patients, distinctively helping them in communication, community activities such as support groups, web-based health information, and e-commerce [31, 32]. Depending on needs,

web sophistication, and familiarity with the specifics of their cancer, the internet can help or hinder patients and their caregivers in these areas. The impact of our website in providing realistic psychosocial intervention is yet to be determined, with the future level of engagement that would enable us to report this and suggest ways of further improvement. We also noted a reduction in the number of website visitors in 2020; this could be attributable to the early days in the COVID-19 pandemic, but the overall interest attests to the fact that in this vulnerable population, web-based support platforms can provide the much-needed access to care and accurate information. There were 22.86 million internet users in Kenya in January 2020, with internet penetration in Kenya of 43% [30]. With the government's current focus on infrastructure and expansion of the internet making inroads into rural Kenya, the increasing popularity of mobile internet, and availability of low-cost smart phones, there are real opportunities for taking advantage of internet access and acceptability of web based forums in educating women and addressing their needs. Consistent with our findings, internet access is known to assist women with BC from the rest of the world in better addressing their psychological and health information needs [33]. Women with MBC in our population indicated a low level of knowledge about their breast cancer diagnosis, having little understanding of the type of their disease, and craved for more, preferably written reports of their disease. Comprehensive information about the type of disease is known to help alleviate stresses and improve QoL [34].

Conclusion

Creating a collaborative group of caregivers and establishing the KMBCN has provided the opportunity for us to understand the psychosocial aspect of this disease better. We recognize that in-person meetings and internet-based platforms are potential resources for reaching out to address the needs of women living with MBC in a low-income country with a constrained health care system. Our study was not designed to evaluate the acceptability and impact of the web-based forums in alleviating the sufferings of this forum; therefore, we cannot concretely conclude the impact of these forums at this time. Nevertheless, we demonstrate that most women with MBC in Kenya have high unmet needs around psychological support, physical and daily living, and on the information. QoL standards are the least for those living in rural areas, having disease worsening, and for those without internet access. Increased unmet needs are associated with a decline in QoL. Women with MBC have very little knowledge about their BC types and treatment. We suggest that networks like KMBCN can potentially prove helpful in addressing needs and improve the QoL of MBC patients

and are an effective way of reaching out to women in rural areas as well. Networks like KMBCN should work towards educating women, providing psychological support, and improving the health care delivery system.

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Data availability Data is available for review.

Code availability NA.

Declarations

Ethics approval Received as appropriate from participating institutions. Ethical approval was sought from relevant institutions as detailed in the ethical approval section of this manuscript.

Consent to participate All participants consented to the study as per study protocol.

Consent for publication Consented.

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