Research article

Effects of stigma on quality of life of cancer survivors: Preliminary evidence from a survivorship programme in Kenya

Maureen J. Koech [b,*], Judy Mwangi [b], Benda Kithaka [a,**], Serah Kimaru [b], Ndinda Kusu [a], Lucy Munyi [a], Sidney Chahonyo [a], Francis Makokha [b]

[a] *KILELE Health, Kenya*
[b] *Mount Kenya University, Kenya*

A B S T R A C T

Globally, cancer is a major public health problem. There is a paucity of information regarding stigma and how it affects the cancer survivors' quality of life (QoL) in Kenya. In a recent report by Globocan, 42,116 new cases and 27,072 fatalities related to cancer were documented in Kenya in 2020. Cancer survivors are more likely to suffer physical and psychological disorders as a result of their poor QoL. The purpose of this study was to evaluate the knowledge, attitudes, and beliefs regarding the stigma associated with the disease as well as how it affects their QoL among a cohort of cancer survivors supported by the KILELE Health Association.

Methods: This research used a cross-sectional design with both quantitative and qualitative methods. The study enrolled 45 cancer survivors from a cohort participating in the KILELE Health Association (KHA) survivors' program. The quantitative data were coded and analyzed using the 26th version of the Statistical Package for Social Sciences (SPSS). Utilizing content analysis, qualitative data was thematically evaluated. In accordance with the study's goals and key measures, the generated transcripts were organized into themes and sub-themes.

Results: Participants' mean age was 44.55 ± 9.89 years. Forty-two of the participants completed the survey and were thus included in the analysis. Cancer survivors reported experiencing low levels of stigma across the following dimensions: awkwardness (2.51 ± 0.75), severity (3.22 ± 1.29), financial discrimination (2.77 ± 1.17), personal responsibility (1.9 ± 1.38), avoidance (1.38 ± 0.68), and policy level stigmatization (5.09 ± 1.70). Awareness raising (97.62%), using communication channels (95.24%), advocacy, and lobbying (92.86%) were the most commonly stated strategies to change people's attitudes in terms of interventions to reduce stigma and improve QoL.

Conclusion: Respondents in this study showed low levels of stigma, which may be due to the support they receive from the KILELE Health Association. Strategic steps in advocacy, publicity, and education are required to end stigmatization to promote awareness and pique people's interest in cancer survivorship. Further research with a larger sample size of cancer survivors from various settings is warranted.

1. Introduction

Cancer is a major issue that affects people of all ages, genders, races, and socioeconomic backgrounds. It is the second most common cause of mortality worldwide, accounting for an estimated 9.6 million deaths [1]. The number of new cases of cancer annually is predicted to reach 15 million by 2020. By 2040, the estimated number of new cancer cases worldwide is likely to surpass 27 million, a 50% rise from the estimated 18.1 million cases in 2018, with low-income countries experiencing the largest increase. It is also evident that most of the 50% rise in cancer cases occurs in low-income nations. Due to advancements in cancer therapy and biomedical research, the majority of formerly incurable malignancies are now treatable, increasing the likelihood of survival for those who have survived the disease [2]. After cardiovascular and infectious illnesses, cancer ranks second among non-communicable diseases. It is the

* Corresponding author.
** Corresponding author.
    E-mail addresses: maurkoe@gmail.com (M.J. Koech), director@kilelehealth.org (B. Kithaka).

third largest cause of death in Kenya [1]. Despite the lack of population-based data, the incidence and mortality of cancer are expected to be about 22,000 and 28,000, respectively. More than 60% of the individuals affected by cancer are under 70 years old. The five most prevalent malignancies in Kenya are colon, breast, cervical, esophageal, and prostate cancer [1].

2. Background

Stigmatization related to health is the act of associating a person with unfavorable traits as a result of their sickness and may lead to adverse effects, including severe psychosomatic problems [3,4]. Stigmatized cancer survivors tend to lose their self-esteem and social status due to discrimination, stereotypes, and isolation from society [5]. In many situations, the effects of cancer-related stigmatization are more upsetting than the disease itself [5]. Stigmatization eventually causes a decrease in quality of life (QoL), especially when combined with social isolation and serious psychological and compliance issues [5–8]. As a result, it is crucial to study stigmatization and its effects on cancer survivors. Stigma towards cancer patients prevents them from developing good coping mechanisms [9].

Quality of Life has been defined as the perception of well-being that arises from an individual's satisfaction or dissatisfaction with those aspects of life that are important to the person [10]. The QoLof cancer survivors is a distinct factor in determining their survivorship. According to the World Health Organization, QoL encompasses an individual's understanding of value systems and culture, including their aspirations, norms, expectations, and concerns. The patient's health status, beliefs, social relationships, environment, and psychological state are all important aspects of QoL. It has been found to offer prognostic data on the prediction of cancer patients' survival duration for different types of cancer [11].

Quality of life is enhanced and diminished by various individual factors and may differ depending on the stage of a cancer diagnosis, the treatment modalities, and the survivorship after the initial treatment phase [12]. The QoL among cancer survivors has four domains: *physical, psychological, social, and spiritual. Physical dimensions* infer that the patient can continue with activities of daily living. The *psychological domain* emphasizes a sense of control over the disease and its threat to life. The *social domain* refers to an individual's ability to re-integrate and maintain meaningful relationships, whereas the *spiritual domain* requires that an individual maintain hope and an understanding of their disease [13].

Cancer patients' QoL may be impacted either favorably or unfavorably. From the time of diagnosis through the course of therapy, a cancer patient's QoL is a critical concern. As a reflection of the patient's perception of the impact cancer has throughout diagnosis and treatment, it is recognized as a metric for providing optimal management and care in oncology practice [14]. Evaluation of cancer patients' QoL may result in improved care services since healthcare providers can identify areas for improvement.

Age, marital status, gender, educational attainment, and employment are sociodemographic variables that impact QoL [2]. It was shown that age was a major predictor of QoL. Younger people had worse social functioning than older individuals, and women scored higher on the QoL scale than males regarding social relationships. This was ascribed to women's higher social contact and participation levels than men's. Marital status and QoL are unrelated, according to Can et al.'s study [15]; the only factor that may have helped married people have a higher QoL than single people is social support. Patients with head and neck Sarcomas and gynecological malignancies have better QoL than those with breast cancer because they have better social outcomes [15].

In comparison to individuals diagnosed at a later age, young breast cancer survivors exhibited considerably lower QoL results. Longer illness duration was linked to improved QoL [16]. Also, compared to those receiving chemotherapy or post-surgery, cancer patients receiving radiotherapy had lower QoL. This is due to the fact that radiation has a higher perceived stress level than both chemotherapy and surgery [16]. It has been observed that Americans who identify as very religious and who practice their religion have a higher QoL than people who do not [17]. Cancer survivors have mentioned spirituality as a coping mechanism for their diagnosis. Their QoL tends to improve as a result of this, increasing their spiritual wellness [18].

A substantial correlation between QoL and a variety of sociodemographic variables, as well as disease characteristics, including the stage of cancer diagnosis and treatment methods, has been found in a number of studies, including [16,17,19].

According to Globocan data, Kenya reported 42,116 new cases and 27,092 deaths in 2020, translating to a 36% chance of surviving a cancer diagnosis [10]. As a result of these poor outcomes, cancer survivors are at an increased risk of developing physical and psychological conditions that affect their overall QoL. Poor QoL and stigma in cancer survivorship present significant challenges to cancer control [20]. One way to improve QoL and also eradicate the stigma attached to cancer survivors is to provide positive role models who have survived cancer and meaningfully involve them in the development of culturally acceptable campaigns that increase knowledge and decrease stigma while promoting primary and secondary prevention of cancer in the community [21]. For this to happen, there was a need to better understand the QoL and stigma issues faced by cancer survivors in Kenya and to design strategies to increase cancer awareness, promote cancer prevention, and fast-track advocacy for resource allocation at the policy level to act as a catalyst to reconstruct a better healthcare system for cancer control post-Covid-19 period.

Thus, there was a need to conduct a pilot study to evaluate the participants' perceived effects of stigma on their cancer journey and how it affects cancer survivors' QoL.

This will inform the creation of a robust evidence-based cancer survivors' navigation programme for community engagement to influence positive perceptions, reduce stigma and increase uptake of preventive cancer control measures in low-resource areas. We also anticipate that the body of knowledge generated will point to the gaps in understanding stigma and QoL measures amongst the target population.

We used the systemic quality of life (SQoL) model as a theoretical framework. The human quality of life in its broadest sense——including mental, physical, social, and cultural well-being—is defined, conceived, and quantified by the SQoL model of 1987 [22]. Based on four systemic components, the SQoL sees human life as an action framework [22]. The framework is used to build a facet description of human QoL, which is considered thorough and exclusive. SQoL comprises the operational mode aspect (expressive,

versatile, holistic, and conservative) and the subsystem facet (character, physical, social, and cultural). Systemic quality of Life accurately evaluates variables that impact QoL. Since its application assesses factors impacting cancer patients' QoL, this theoretical model was deemed fit for the study and thus applied.

3. Aim

Hence, the main aim of this study was to carry out a pilot study on the effects of stigma on the QoL of cancer survivors in Nairobi County, Kenya.

4. Objectives

1. Evaluate sources and prevalence of stigma towards cancer survivors and its impact on cancer prevention and optimal QoL;
2. Determine the role of cancer survivors as community champions to help reduce stigma and improve the adoption of preventative approaches in cancer prevention;
3. Identify possible interventions to counter stigma and improve the QoL for women cancer survivors at the community level.

5. Methodology

5.1. Study setting

KILELE Health is a Nairobi-based organization that aims to involve survivors, partners, and other stakeholders in improving the understanding of cancer survival, focusing on enhancing the QoL for cancer survivors. Participants were selected from the above mentioned cancer survivors' support group. The group's first batch of cancer survivors, with differing experiences of survival, was drawn from Nairobi's informal slums. These low-resource settings included the slums of Kawangware and Dandora.

5.2. Study population

The study focused on cancer patients who had finished their treatment during the previous five years. Participants who agreed to sign an informed consent form and were at least 18 years old were included in the study. Anyone who had received a cancer diagnosis and treatment within the previous five years, including recurrences or secondary malignancies or tumors, was included in the study. Cancer survivors under 18 years and any qualified individuals who refused to sign the consent form were excluded from the study. Following the recruitment of 45 participants who met the study's inclusion criteria, 42 of them completed the survey in its entirety and were thus included in the analysis, yielding a response rate of 93.33%.

5.3. Data collection

The data collection was done from November 2021 to January 2022. A cross-sectional design with a mixed-method strategy was applied. By offering a more comprehensive picture that can improve the description and comprehension of the phenomenon, the mixed-methods study design seeks to provide a richer and deeper knowledge [23].

The convenience sampling strategy was employed to enlist study participants. As part of the sample size, all women cancer survivors who met the inclusion requirements under KILELE Health's survivorship program were included.

The researchers generated Key Informant Interviews (KII) and a Focus group discussion guide (FGD); however, they adopted The Cancer Stigma Scale (CASS) questionnaire to measure the stigma. The Functional Evaluation of Chronic Illness, Therapy for Measuring Quality Matrix, was used to evaluate the QoL among cancer survivors [24] The participants' demographic data and statistics on the prevalence of stigma were gathered quantitatively using a structured questionnaire administered by a researcher. The CASS questionnaire was adopted to guarantee data comparability with the current worldwide standards [25]. The prevalence of stigma was measured using the six stigma indicators from the cancer stigma scale to determine the sources, prevalence, and impact of stigma against cancer survivors, as well as how it affects cancer prevention and the quality of life. These indicators included awkwardness, severity, financial discrimination, personal responsibility, avoidance, and policy-level stigmatization. A five-point Likert scale (1 = Strongly disagree, 2 = Moderately disagree, 3 = Slightly disagree, 4 = Slightly agree, 5 = Moderately agree, 6 = Strongly agree, and 7 = Not sure) was used. Using a KII, we gathered qualitative information on the path of cancer survivors, perceptions of cancer survivors on how the general public perceives cancer survivors, and measures to change people's attitudes towards cancer and cancer survivors.

5.4. Main outcome measures

Respondents were questioned about their age (0 = 18–25, 1 = 26–35; 2 = 36–45; 3 = 46–55, 4 = 56–65; 5 = ; Above 65 years, marital status (0 = married; 1 = separated; 2 = single; 3 = widowed), level of education (0 = did not attend school; 1 = primary; 2 = secondary; 3 = technical/vocational; 4 = university), occupation (0 = formal employment; 1 = house assistance; 2 = house wife; 3 = ordinary hustling for survival; 4 = self-employed; 5 = temporary employment) and lastly on demographic data, description of cancer status (0 = both a cancer survivor and caregiver; 1 = cancer survival; 2 = cancer patients).

Participants were also asked about the type of cancer survived (0 = anal cancer; 1 = breast cancer; 2 = post nasal space cancer; 3 =

cancer of the throat stage 1; 4 = cervical cancer; 5 = colorectal cancer; 6 = embryonal rhabdomyosarcoma; 7 = eye cancer; 8 = leukemia; 9 = nasopharyngeal cancer; 10 = nasopharyngeal carcinoma; 11 = non-lymphoma; Hodgkin's 12 = pancreatic cancer; 13 = prostate cancer; 14 = sarcoma; 15 = synovial sarcoma). Survivorship years were questioned for (0 = 0–5; 1 = 6–10; 2 = 11–15; 3 = 16–20; and 4 = more than 20 years). Using a scoring system for cancer stigma that has 25 variables (1 = Strongly disagree, 2 = Moderately disagree, 3 = Slightly disagree, 4 = Slightly agree, 5 = Moderately agree, 6 = Strongly agree, and 7 = Not sure), data on perceptions of cancer stigma and how it manifest was gathered. The scale measured six dimensions of stigma: severity, responsibility, awkwardness, avoidance, discrimination, and policy opposition.

5.5. Data analysis

Statistical Package for Social Sciences (SPSS) version 26 was used to code and analyze the quantitative data that was gathered. A univariate analysis was conducted to describe participants and their characteristics. For qualitative data, thematic content analysis was performed. Where respondents spoke Kiswahili, in-depth interview recordings were made and later verbatimly transcribed and translated into English. The generated transcripts were organized into themes and sub-themes per the study's objectives and key metrics. The intercoder reliability was determined using Cohen's Kappa formula to guarantee the validity of the qualitative coding process. A complete agreement was found with a value of 0.86.

5.6. Ethics statement

Given that the study involved human subjects, the team took all reasonable precautions to ensure the participants' mental and physical health. Each participant was given a special identification number to safeguard the individual's identity. The participants were informed of the study's goal before data collection, and their written consent was acquired. This research, with reference number MKU/ERC/1075, was approved by the Institutional Research Ethics and Review Committee (IREC) of Mount Kenya University. Permission to perform the study was given by the National Commission for Science, Technology, and Innovation (NACOSTI) under license number NACOSTI/P/22/15133. The respondents received no incentives to participate in the study; participation was entirely voluntary. The KILELE survivorship program participants were advised that their data would only be used for this research and any future relevant studies, and they consented.

6. Results

The main outcomes of the study are guided by the major themes derived from the objectives of the study; however, the demographic information of the respondents have been provided to offer an insight into the context in which this study was undertaken. Table 1 presents the socio-demographic characteristics of the participants. The mean age of the selected participants was 44.55 ± 9.89, and the range was 18–70 years.

Regarding marital status, nearly half of the participants (n = 18, 42.86%) reported being single, sixteen (38.10%) reported being married, and 4(9.2%) reported being separated from their spouses and widowed, respectively.

On education, the highest percentage (n = 18, 42.86%) of the respondents attained university/college education, and almost a

Table 1
Socio-demographic characteristics (n = 42).

Variable	Categories	Valid percentage %
Age	26–35	19.05
	36–45	35.71
	46–55	33.33
	56–65	9.52
	>65	2.38
Marital status	Married	38.10
	Separated	9.52
	Single	42.86
	Widowed	9.52
Level of education	Did not attend school	2.38
	Primary	7.14
	Secondary	23.81
	Technical/Vocational	23.81
	University/college degree	42.86
Cancer status	Both cancer survivor and caregiver	23.81
	Cancer survivor	76.19
Occupation	Self-employed	54.76
	Formal employment-Government or private sector	30.95
	Small traders	7.14
	House help	2.38
	Housewife	2.38
	Temporary employee	2.38

quarter (n = 10, 23.81%) attended technical/vocational institute and secondary school, respectively while the least percentage did not attend school (n = 1, 2.38%).

Regarding self-description of cancer status, the largest percentage (n = 31, 76.19%) of the respondents described themselves as cancer survivors, followed by those who described themselves as both cancer survivors and caregivers (n = 11, 23.81%).

Concerning the occupation of the respondents, most of the participants (n = 23, 54.76%) were self-employed. However, the least percentage (n = 1, 2.38%) were house helps, housewives, and temporary employees respectively.

Sources of stigma among cancer survivors

To address the first objective, which was to determine the sources of stigma among cancer survivors, the study focused on the prevalence of stigma and the experiences that cancer survivors had following their diagnosis.

Table 2 below shows the prevalence of stigma among cancer survivors. Concerning awkwardness, cancer survivors were asked to respond to the following questions to gauge their level of awkwardness: I would feel embarrassed discussing cancer with someone who had it; I would find it hard to talk to someone with cancer; I would find it difficult being around someone with cancer; I would feel comfortable around someone with cancer, and I would feel at ease around someone with cancer. The responses to all the questions within this parameter were calculated to determine the mean of awkwardness as a single value. The overall mean score for awkwardness was 2.51 ± 0.75. The responses to the five questions above regarding talking, being around, feeling comfortable, and at ease with someone diagnosed with cancer demonstrate minimal awkwardness. This means that cancer survivors can effectively help and counsel cancer patients as they navigate the disease.

About severity the following questions were asked to gauge the level of severity: cancer devastates the lives of those it touches; cancer usually ruins close personal relationships; having cancer usually ruins a person's career; once you have had cancer, you will never be 'normal' again, and getting cancer means having to mentally prepare oneself for death. As displayed in Table 2, their answers produced a mean score of 3.22 ± 1.29. Because they stand for the success story that cancer is curable, the participants' responses to this indicator demonstrated that the severity of the cancer is low.

Concerning financial discrimination, the following questions were posed to them: It is acceptable for insurance companies to reconsider a policy if someone has cancer; banks should be allowed to refuse mortgage applications for cancer-related reasons, and it is acceptable for banks to refuse to give loans to people with cancer. According to Table 2, the average score for financial discrimination against cancer survivors was 2.77 ± 1.17. This suggests that there is only a mild level of financial discrimination against cancer survivors, according to those who have experienced it.

On personal responsibility, cancer survivors were asked the following questions to measure the stigma associated with personal responsibility: To measure the stigma related to personal responsibility, cancer survivors were asked the following questions: a person with cancer is to blame for their condition; a person with cancer is accountable for their condition; a person with cancer is liable for their condition, and if a person has cancer, it is probably their fault. The total mean score shown in Table 2 was 1.90 ± 1.38. The respondent firmly disagreed with all four of the questions intended to measure the cancer patients' responsibility. This implies that the cancer patient is not to blame for the illness, that they are not accountable or responsible for their symptoms, and that it is not their fault that they have cancer.

In relation to avoidance, cancer survivors' experience was evaluated using five questions. They included the following: I would try to avoid a person with cancer; I would feel angered by someone with cancer; I would feel irritated by someone with cancer; I would distance myself physically from someone with cancer, and if a colleague had cancer, I would try to avoid them. Their responses totalled a mean of 1.38 ± 0.68, as shown in Table 2. Respondents vehemently disagreed with the five questions that focused on avoidance as a form of stigma against cancer patients. Therefore, it may be concluded that cancer survivors do not avoid cancer patients.

Pertaining policy level stigmatization, the respondents were required to answer the following questions: The needs of people with cancer should be given top priority; more government funding should be spent on the care and treatment of those with cancer, and we have a responsibility to provide the best possible care to people with cancer. The results on the level of policy stigmatization are shown in Table 2. The mean total was 5.09 ± 1.70, indicating that most participants strongly agreed that cancer patients should be prioritized, that more government funding should be allocated for cancer care and treatment, and that cancer survivors are responsible for giving cancer patients the best care possible.

Regarding types of cancer, according to Fig. 1, close to half of the cancer respondents (n = 20, 47.62%) had been diagnosed with breast cancer, followed by cervical cancer (n = 8, 19.04%). When asked what thoughts they had after learning of their diagnosis, the majority of them said that they felt like dying, they fell into depression, some of them entered a state of denial, and they were unable to imagine how they would make it through the ordeal of chemotherapy, as well as the financial burdens and health deterioration that would follow. One of the discussants narrated: *"Just being told my results read I had cancer was devastating. I saw death because I knew I*

Table 2
Prevalence of stigma towards cancer survivors.

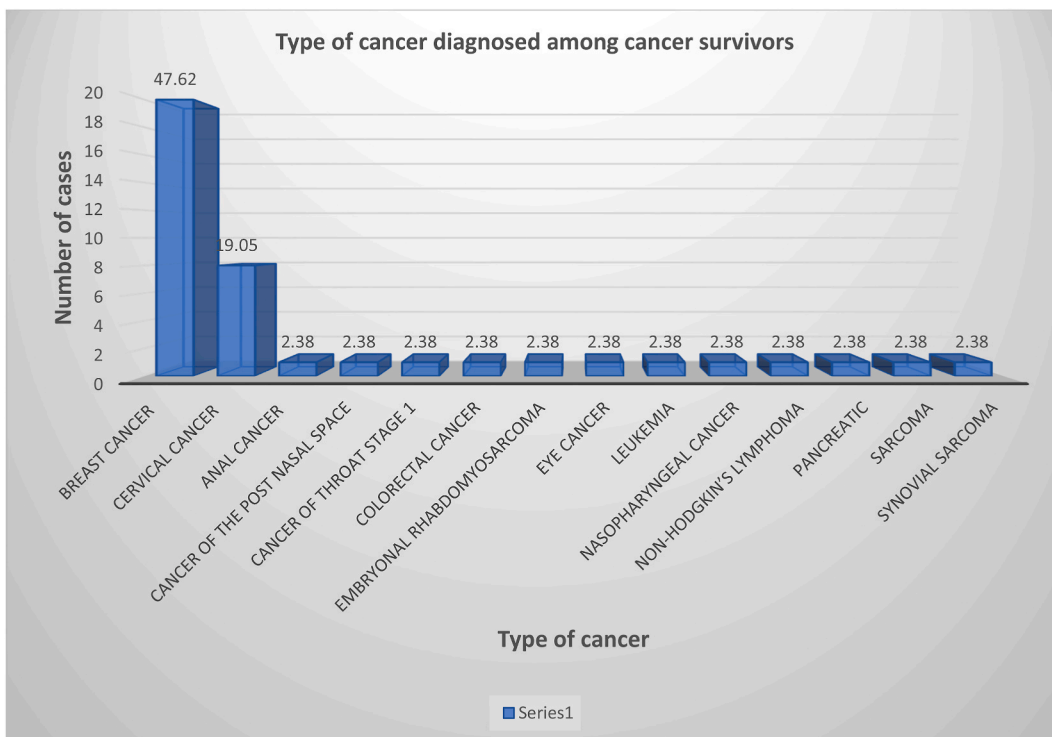| Domain	N	Minimum	Maximum	Mean	SD
Awkwardness	42	1.00	4.00	2.51	0.75
Severity	42	1.20	6.00	3.22	1.29
Financial discrimination	42	1.00	4.67	2.77	1.17
Personal responsibility	42	1.00	7.00	1.90	1.38
Avoidance	42	1.00	4.00	1.38	0.68
Policy level stigmatization	42	1.00	6.00	5.09	1.70

Fig. 1. Type of cancer diagnosed among cancer survivors.

would not get the finances to cater for the treatment since my mum had been diagnosed the previous year, and a Harambee was conducted to raise funds to cater for her treatment, so I wasn't standing a chance."

When asked who they told initially, a handful said they did not tell anyone; nevertheless, the majority said they informed their family members, including their father, mother, husbands, sons, daughters, and cousins. A select handful informed their closest friends and neighbors. This was reported by one respondent: *"I told my cousin. I then told my neighbor who had been helping me a lot. I then told my youngest daughter, who had found out on her own, despite me trying to hide my medical results."*

In terms of survivorship, about 47.62% (n = 20)stated that they had survived for five years or less, 33.33% (n = 14)between six and ten years, and 4.76% (n = 2) had both survived for between sixteen and twenty years and more than twenty years respectively. Additionally, 80.95% (n = 34) of the participants reported having a secondary cancer diagnosis or experiencing a cancer recurrence, while 19.05% (n = 8) did not report receiving either of those diagnoses.

Regarding coping with the diagnosis and treatment phases, 50% (n = 21) of the respondents indicated that they did not cope well with the diagnosis and treatment of cancer, while 45.21% (n = 19) and 4.76% (n = 2) reported having a good or excellent time coping respectively. Qualitative research revealed that those who coped well had much support from their family and friends and were able to accept, adopt, and adjust as needed, whereas participants who coped badly, primarily despite having family support, were unable to accept and adjust as needed. To support this, one respondent provided the following information: *"Though it took time, I finally accepted my fate and made peace with the fact that I needed to go through the treatment for me to get back on my feet. I learned to love my body again after the mastectomy and I have consistently and continually been doing my annual checkups to ensure all is well. My parents funded my treatment and I am eternally grateful to them, am glad I coped through it all successfully. Family and friends were a big support system during this period."*

About post-treatment care, a total of 59.52% (n = 25) of the respondents said they received information, compared to 40.48% (n = 17) who said they did not. The respondents were given information about post-treatment care that covered topics like life after cancer treatment, ways to lessen the short- and long-term effects of cancer treatment, the importance of checking one's diet, weight, and physical health, and the importance of eating a balanced diet, as well as information about mastectomy, chemotherapy, radiology, and treatment costs. One respondent said the following: *"My doctor advised me. Not to overdo. Not to neglect and get out of bed and make a move around the house. "*Another respondent in support of this reported that: *"I was advised to continue checking on my diet, psychological practices, and visiting clinic".* The qualitative research results also showed that the cancer survivors learned a lot about cancer that they did not know before they were diagnosed. Part of this information included how to deal with the emotional, financial, and physical long-term impacts of cancer treatment, post-cancer care, and the importance of nutrition in cancer management. A discussant alluded: *"I know that early detection can treat; cancer screening is also a must it is better to be safe than sorry."*

With regard to post-treatment side effects information, the percentage of cancer survivors who received and those who did not receive information about post-treatment side effects was equal at 50% (n = 21). Some of the side effects mentioned were hearing loss,

compromised saliva glands, weakened immunity, abdominal pains, painful rotator cuffs on the affected side, headaches and hot flashes, exhaustion, hair loss, weight gain, social stigma, marital uncertainty, stress and despair, and generalized body sluggishness.

Concerning ways that could be introduced to make diagnosis information bearable, as shown in Table 3, 66.67% of respondents thought something could have been done to make the diagnosis easier to handle, while the remaining 33.33% said nothing extra could have been done to make the diagnosis bearable. These results were reinforced by qualitative findings where the majority of the participants believed that the doctors and hospital staff could have done more before and after diagnosis. Others thought they should have been permitted to travel and come with a family member or friend. They indicated that they may have received counselling services and comprehensive information on the disease, potential side effects, and necessities for survival. The cancer survivors reported the following in support of their viewpoints: *"Yes. Not disclosing it without proper empathy and not giving hopeless sayings." "I wish they had sent me to find someone close to me instead of just informing me. … the doctor just told me by the way."*

Regarding cancer interference in the family life of cancer survivors, all cancer survivors confirmed that cancer had interfered with their lives in some way, as seen in Table 3. All participants (n = 42, 100%) claimed that cancer harmed their social life, 97.62% (n = 41) of participants stated cancer impacted negatively on their financial situation, and 66.67% (n = 28) said cancer impacted negatively on their businesses. These results were in agreement with qualitative findings as reported by most of the respondents. The cancer survivors reported the following in support of these results: *"I cannot get another child anymore, I can no longer interact with other family members because I look like an outcast, my child is stressed up with the fact that her mum is sick and it stresses me out because she can't concentrate in her school work anymore, I am alone in my journey I don't receive family help or* support.*"*

"Cancer takes every penny available plus also selling some items for treatment and also everybody is affected psychologically."

When cancer survivors were asked about the attitudes of people toward cancer, the majority of them said that cancer is seen as a death sentence (n = 42, 100%), followed by the notion that it is very expensive to treat at 97.62% (n = 41) and that it is stigmatized at 95.2% (n = 40). Cancer survivors reported the following in a qualitative study in support of these findings: *"It is a death sentence; treatment is harsher, and it robs you of everything during and after possible treatment."*

"Some believe it's a death sentence while it's not. Others have superstitious beliefs. Some think it's not manageable and believe it's too expensive to cure."

In terms of public opinion of cancer survivors, as demonstrated in Table 3, all respondents (n = 42, 100%) indicated that people believe cancer survivors are going to die soon, followed by disability and vulnerability, both at 83.33% (n = 35), respectively. The least number of respondents believed that cancer survivors are bewitched and dejected, at 59.52% (n = 25) and 47.62% (n = 20), respectively. Cancer survivors backed up these findings by saying the following: *"They are disabled. Unable to care for themselves or contribute to society."*

"Some believe that they are not truly healed. Some think it is infectious, while it's not. Some disassociate with them as they believe they can't get cured."

As shown in Table 3 above, when asked what influences people's attitudes toward cancer survivors and the disease as a whole, all

Table 3
Attitude towards Cancer and cancer survivors.

Are there ways that could have been introduced to make diagnosis information bearable?	Percentage, n (%)
Yes	28 (66.67)
No	14 (33.33)
Cancer Interference on the Family Life of Cancer Survivors	
Social life	42 (100)
Financial capabilities	41 (97.62)
Family life	40 (95.24)
Work/Employment	30 (71.43)
Businesses	28 (66.67)
Perceptions of cancer among the general public	
Death sentence	42 (100)
Very expensive to manage	41 (97.62)
Stigma	40 (95.24)
Drains resources	39 (92.86)
Curses/bewitched	38 (90.48)
Not curable	37 (88.10)
Public opinion of Cancer Survivors	
Walking dead	42 (100)
Disabled	35 (83.33)
Vulnerable	35 (83.33)
Strong, positive, and courageous	26 (61.90)
Cursed/bewitched	25 (59.52)
Dejected	20 (47.62)
Factors affecting people's attitudes, either positively or negatively	
Lack of information	42 (100)
Misinformation	41(97.62)
Misconceptions about cancer	40 (95.24)
Ignorance and myths	39 (92.86)
Rate of death	38 (90.48)
Its extended period of treatment	35 (83.3)

participants (n = 42) indicated a lack of information, followed by misinformation at 97.62% (n = 41) and misconceptions about cancer at 95.24% (n = 40). Consistent with the quantitative findings, one of the cancer survivors stated the following: *"Just thinking about the disease and how it has killed many people, so they fear it"* *"Believes that it's a curse from God"* *"Negative reaction because of lack of knowledge about cancer"* *"Knowing from God's word that in the last days, mankind will experience such pestilences."*

6.1. Role of cancer survivors as community champions to reduce stigma

To measure the second objective of determining the role of cancer survivors as community champions to help reduce stigma and improve the adoption of preventative approaches in cancer prevention, the study focused on post-treatment challenges, the needs of cancer survivors, providers of support services to cancer survivors, support services currently needed but not provided/available.

Stigmatization, rated at 13.05%, was the most frequently mentioned post-treatment challenge as shown in Table 4, followed by financial constraints at 18.52%. In contrast, the denial of health and life insurance, discrimination, regaining self-esteem, a lack of medical follow-up, body pain, the cost of prostheses and compression sleeves, reintegration back into society, and work-related challenges were rated at 1.23% each. Similarly, qualitative data revealed that the two main challenges faced by cancer survivors were financial hardship and social stigmatization. These were reported by the respondents: *There are people I owe cash-a lot of them-including Kenyatta National Hospital. Everyone is waiting for me to finish my treatment so that I can pay up. Even at the place I stay, I have arrears of up to* 11 *months. What is stressing me out is my rent because as soon as I am done with radiotherapy, agents will be here to collect the debt. Part of me is praying I don't finish the radiotherapy soon."*

"*I have a daughter who has just finished form four, and I don't know how she will get to campus because the school paid for her final year school fees due to the situation, but now I don't know how to do it from here.*"

The most often reported needs were emotional and psychosocial support (26.44 %), followed by financial help (21.84 %), and a supply of adequate and high-quality food (9.20 %).

Regarding the providers of support services to cancer survivors, the highest percentage of participants reported that they receive support services from patient/survivor support groups at 40.48%, followed by faith-based organizations at 21.43% and non-governmental organizations at 19.05%.

With relation to support services that are required but not offered or available, the majority of participants (40.43%) stated financial assistance, followed by income-generating opportunities and free medical assessment and treatment at 14.89% each as most needed support services. Basic needs, government support, and prosthesis services, each at 4.26%, were the least mentioned support services for respondents. Qualitative findings consistently pointed to the same outcomes. Supporting this, one cancer survivor reported the following: *"I wish someone can pay for me another type of chemo (Herceptin) which was recommended but have never done it because it's very costly and the NHIF offers very little"*.

This is what another cancer survivor had to say: *"As a survivor turned caregiver, I need* financial support *to provide nutrition to more cancer patients.*

Table 4
Post-treatment challenges encountered by cancer survivors.

Post-treatment challenges	Percentage, n (%)
Financial constraints	15 (18.52)
Stigmatization	13 (13.05)
Side effects of treatment	6 (7.41)
Health and nutrition issues	6 (7.41)
Emotional and psychological problems	5 (6.17)
General body weakness	4 (4.94)
Lost wages and jobs	4 (4.94)
Lack of affordable healthcare services	3 (3.70)
Treatment cost is very high	3 (3.70)
Lack of support	3 (3.70)
Coping with the body changes problems	2 (2.47)
Increasing economic burdens	2 (2.47)
Lack of cancer facilities and services at the nearby dispensaries and health centers	2 (2.47)
Fear of recurrence	2 (2.47)
Loss of body parts	2 (2.47)
Lack of adequate basic provisions including food and water	2 (2.47)
Denial of health insurance and life insurance coverage	1 (1.23)
Discrimination	1 (1.23)
Gaining back self-esteem	1 (1.23)
Lack of medical follow-up	1 (1.23)
Body pain	1 (1.23)
Prosthesis and compressions sleeves are not affordable	1 (1.23)
Problems of Reintegrating back into Society	1 (1.23)
Work-related challenges	1 (1.23)

6.2. Possible interventions to counter stigma and improve the QoL for women cancer survivors

To address the third objective, focusing on the identification of possible interventions to counter stigma and improve the QoLfor women cancer survivors at the community level, the study focused on ways of rectifying negative attitudes reinforcing cancer stigma towards cancer survivors.

When asked about potential strategies for promoting positive attitudes, almost all respondents (n = 41, 97.62%) mentioned raising awareness, which was followed by the use of communication channels like social media and adverts (n = 40, 95.24%). Mass education was the least mentioned strategy at 80.95% (n = 34). In agreement with the findings, the respondents reported the following: *"Through a lot of awareness and advocacy, cancer survivors talk about their positive outcomes."*

"Through positive advocacy and sharing of positive lived experiences of cancer survivors."

7. Discussion

This study recruited its participants from the KILELE Health Association cohort. The study was carried out to examine how stigma affects cancer survivors' QoL in Kenya, an area that has not received a lot of attention. Analysis revealed that cancer survivors exhibited stigma but at a very low level. This could be linked to the provision of good psychosocial support from the organization. These findings were in line with an earlier study in the UK, where it was discovered that cancer survivors experience less stigma [26]. Breast cancer affected the majority of cancer survivors. This is consistent with data that indicates breast cancer is the second most common type of cancer globally [27]. Even though lung cancer is one of the most common cancers worldwide, none of the study participants have ever had the disease. This may be because of the fact that the study was a pilot and, as such it had a small sample size (n = 42), which does not accurately represent Kenya's cancer survivorship population.

According to the analysis, cancer survivors significantly disagreed with the statements that they would feel awkward talking about cancer, conversing with someone who has cancer, and finding it challenging being near someone who has cancer. This suggests that cancer survivors are more willing to talk about their experiences. The majority of participants resoundingly concurred that being near someone with cancer makes them feel relaxed and at peace. This demonstrates that there isn't much awkwardness. These findings contrasted with those of a study conducted in Israel, which found that Druze men, as opposed to women, felt more uneasy about or discussing cancer with someone who had breast cancer [28]. In another study, men who had lost a testicle as a result of testicular cancer reported that the feeling of embarrassment and shame was more as compared to being teased about having a small penis, being diagnosed sterile, or having a breakup with a loved one [29].

Participants strongly disagreed with all five of the assertions made to them regarding the avoidance scale. This implies that cancer survivors do not avoid cancer patients. Divergently, Druze men intentionally avoided interactions with those who have breast cancer [30]. In their study of enacted discrimination, some males diagnosed with prostate cancer were purposefully avoided or accused of not taking care of themselves and were responsible for failing to act sooner when the symptoms initially appeared [31]. Pertaining to the policy opposition scale, the mean overall score in our current study was 1.87 ± 1.70, showing cancer survivors believe government authorities should give cancer proper attention.

Similarly, research conducted by Gershfeld-Litvin et al. [28,30], argued that breast cancer should be a top priority for government policies and spending. Ratings on personal responsibility suggest that cancer survivors strongly believe that it is not a person's fault to have cancer. On the other hand, a prior study on personal responsibility indicated that if someone is diagnosed with breast cancer, it is their responsibility [30].

The majority of participants said that something could have been done to make the diagnosis easier to manage when it came to potential strategies to introduce to make diagnosis information bearable. The findings of the present study corroborated those made by Ref. [32], who claimed that having relatives nearby is crucial for emotional support. Newly diagnosed cancer patients may experience short-term mental incapacity after receiving cancer diagnosis news, which leads to poor comprehension of additional information related to prognosis and treatment plan [33]. Family members and friends play an important role in helping cancer patients cope with cancer diagnosis [34].

All cancer survivors claimed that the general population believes that having cancer is a death sentence. In Iran, a comparable quantitative study indicated that 20% of cancer survivors thought cancer could not be cured [35]. These findings were in line with a qualitative study from the UK that discovered the visceral dread of cancer was pervasive and people struggled to regulate their negative ideas about the disease despite advances in outcomes [36]. In this study, the majority of cancer survivors claimed that the general public views them as being helpless, disabled, and vulnerable. These results show that there are more cancer survivors now than there used to be. However, there is still room for improvement in the interventions made to raise public awareness of cancer survivors. These findings echo those of an earlier study in which participants said that people were more inclined to think of cancer survivors as having physical, emotional, and social impairments [37].

In this study, financial help was scored highly regarding support services that are required but not provided, followed by income-generating opportunities and free medical evaluation. This finding's diverged from those of a Korean study that indicated support for coping with the fear of recurrence was the top unmet need among breast cancer survivors [38]. Stigmatization and financial restraints were the post-treatment issues that were most frequently highlighted in this research. Previous research has shown that, except for genitourinary cancer, anxiety was the most common concern for patients with all tumor types [39].

In terms of coping with the treatment and diagnosis phases, the majority of participants said they did not cope well. According to the survivors, there was little support accorded to them by family and friends. These findings were not in line with a prior study of elderly cancer survivors, which found that they valued proactive care, social support, and instrumental or active approaches to dealing

with their condition [40]. The results of this latest study may be explained by the fact that the study's cohort was younger and an urban population, indicating that close family members were in their rural areas.

Regarding interventions to counter stigma and improve QoL, most participants suggested increasing awareness and using communication channels like social media and advertisements. In a study carried out in the UK, news items were utilized to create an emotionally charged narrative about the public stigma towards those who had not had their cervix screened for cancer [41]. The authors of a different study on cancer-related stigma intervention employed telephone acceptance-focused cognitive behavioral therapy to combat stigma among lung cancer patients [42].

8. Limitations

The primary limitation of this research was its exclusive use of univariate analysis. Bivariate and multivariate analysis should be considered in future research. The cross-sectional design of the study is a significant drawback. This is because the design provides data at one point in time, making it impossible to establish a causal relationship between stigma and cancer survivors' QoL. Longitudinal investigations are strongly warranted to demonstrate causal connections. There is a chance that the error rate and statistical power were adversely affected by the limited sample size. These research findings are in line with those of earlier research done in other countries, indicating that the impact of stigma on cancer survivors' QoL is widespread.

9. Implications

The findings from this study offer an understanding of the specific dimensions of stigma experienced by cancer survivors (e.g., avoidance, personal responsibility), which helps guide the development of tailored interventions to address these aspects. Besides, the findings underscore the need for advocating for policies to protect the rights and well-being of cancer survivors and elimination of discrimination. Since the study suggests that support programs, such as those provided by the KILELE Health program, can contribute to reducing cancer-related stigma among the survivors, it implies that investing and expanding such initiatives may improve the QoL of the cancer survivors, especially their psychosocial well-being. Future scholars ought to add to the body of knowledge by investigating strategies for enhancing the QoL of cancer survivors. The present study recommends that strategic measures in advocacy, publicity, and education are needed to raise awareness and ignite people's interest in cancer survivorship to minimize the rate of stigmatization, as revealed by the study. Given that the current study is a pilot, there is a need to undertake a large-scale study focusing on a large population of cancer survivors, especially those not under a support group.

10. Conclusion

According to this research, there was less stigma, which may be due to the support KILELE Health Association provides cancer survivors. The results of this study have given direction for designing interventions to combat cancer stigma among the general public and among cancer patients themselves.

Data availability statement

Upon a reasonable request, the authors will provide the raw data that underpins the conclusions of this article without undue reservation.

Positionality statement

The authors in this article are multidisciplinary representing the academia from Mount Kenya University (MK, JM, SK, FM) and the industry from KILELE Health (BK, NK, LM, SC). The team from KILELE Health self-declared themselves as cancer survivor champions and has a lot of experience in cancer care and stigma. They were mainly involved in data collection because of their position in championing cancer survivors' care and ending stigma, allowing the study participants to feel comfortable sharing their lived experiences in a way they felt could best express their thoughts and feelings. The team from academia offered research skills in developing the tools for data collection, data analysis, and editing. It is likely, however, that our backgrounds influenced our interpretations of the data. To avoid speaking for the data, both teams made efforts to shield the existing bias, and all members of the teams were involved in interpolating the data. The data was discussed to ensure the team understood the thinking and perspectives of the participants.

CRediT authorship contribution statement

Maureen J. Koech: Writing – review & editing, Writing – original draft, Supervision, Software, Methodology, Investigation, Formal analysis, Data curation. **Judy Mwangi:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Project administration, Methodology, Formal analysis, Data curation. **Benda Kithaka:** Writing – review & editing, Visualization, Validation, Supervision, Project administration, Methodology, Investigation, Data curation, Conceptualization. **Serah Kimaru:** Writing – review & editing, Visualization, Validation, Supervision, Project administration, Methodology, Investigation, Data curation. **Ndinda Kusu:** Project administration, Methodology, Investigation, Data curation. **Lucy Munyi:** Methodology, Investigation, Data curation. **Sidney Chahonyo:** Methodology, Investigation, Data curation. **Francis Makokha:** Writing – review & editing,

Visualization, Validation, Project administration, Methodology, Investigation, Data curation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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