Perceived health-related quality of life among patients living with cancer at Kamuzu Central Hospital in Malawi

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Patients living with cancer and their families experience several challenges that affect their health-related quality of life (HRQOL). Perceived factors affecting quality of life (QOL) among people living with cancer have rarely been studied. We aimed at exploring the factors perceived to be associated with health-related quality of life among people living with cancer attending to a National Cancer Centre at Kamuzu Central Hospital in Malawi. Between May and June 2022, we conducted a qualitative study to assess perceptions and the in-depth lived experiences for people living with cancer, caregivers and healthcare workers at the cancer center on health-related quality of life. We purposively selected and interviewed thirteen participants. Interviews were transcribed, coded using NVivo 12 and analyzed using thematic analysis. Two broad categories of emerging themes of quality of life were identified. These included: (a) individual level factors such as experiences with diagnosis and treatment, changes on physical, psychological and social health, support received, benefits and challenges, (b) facility level factors such as availability of resources, relationship with providers, satisfaction with cancer care, facility organization, facilitators and barriers to improved quality of life. This study has highlighted the importance of physical, psychological, and social factors as key determinants perceived to be affecting health-related quality of life among patients living with cancer and their caregivers at the National Cancer Centre, Kamuzu Central Hospital in Malawi. The QOL challenges experienced by patients and their caregivers, implied that cancer care interventions should consider a holistic approach to cover all dimensions of life in order to improve health-related quality of life among patients living with cancer.

**Introduction**

Cancer is a growing health problem worldwide with an estimated 19.3 million new cases and almost 10.0 million cancer deaths having occurred in 2020. The global cancer burden was projected to reach 28.4 million cases in 2040, an increase by 47% from 2020 records with a larger increase in Low and Middle Income Countries (LMICs) countries (64–95%) than High Income Countries (HICs) (32–56%). In Malawi, cancers contributed to 16% of Disability-Adjusted Life Years (DALYs) due to Non-Communicable Diseases (NCDs) in 2015. The top five common cancers included: Kaposi sarcoma (34.1%), uterine cervix (25.4%), oesophageal (12.0%), non-Hodgkin's lymphoma (5.7%) and urinary bladder (2.9%) in 2020.

Patients living with cancer and their families experience several challenges that affect their health-related quality of life (HRQOL). Both patients and their families experience denial following diagnosis, emotional turmoil, lack of concentration, sleep difficulties, loss of appetite, irritability and intrusive thoughts about the future. They also go through processes of readjusting and adapting which included breaking the "bad news" of cancer diagnosis to other family members, managing household and childcare responsibilities, negotiating changes in family and social roles, and interferences with life plans. The World Health organization (WHO) defined quality of life (QOL) as individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concern. Therefore, QOL is a dynamic concept, covering perceptions of both the positive and negative aspects of the dimensions of physical, emotional, social, and cognitive function arising from patient reaction to results of diagnostic tests, the stages of sadness, grief and anger.

Studies that have been conducted on QOL among patients living with cancer and their families had reported wide range of perceived factors contributing to the severity of QOL-related health problems. The perceived factors ranged from lack of staff, lack of continuity of care, professional incompetence or disorganized healthcare services contributing to poor QOL as reported in Norway. Other participants complained of inadequate information to patients and family members generating unpredictable and distressing final illness trajectories. Patients in Belgium, Italy as well as in Ghana had reported physical aspects such as skin conditions, nausea, fatigue, risk of infections sensory abnormalities (e.g., pain); and changes in physical appearance were highlighted to negatively affect quality of life. Psychologically, patients were worried about uncertainties regarding their future health state, and a lower degree of autonomy and independence. Socially, people living with cancer noted the importance of communication with healthcare workers and social interaction with families and friends for improved QOL. Some patients living with prostate cancer in Uganda had reported lack of information and unavailability of healthcare workers, state of doubt, sense of loneliness and lack of support groups as main factors associated with poor health related quality of life. Data on the perceived factors affecting patients living with cancer was almost non-existent in Malawi. Lack of studies evaluating QOL among cancer patients made it difficult to ascertain type of physical, psychological and social problems experienced by them and how to approach them. We therefore conducted the current study aiming at exploring the determinants of perceived health-related QOL among patients living with cancer at a National Cancer Center based at Kamuzu Central Hospital in Malawi.

**Methods And Materials**

**Study design and setting**

We conducted a qualitative study to explore lived experiences and perceptions of patients, their caregivers and healthcare workers (HCWs) on health-related quality of life at the National Cancer Centre at Kamuzu Central Hospital (KCH). The National Cancer Center at KCH was a newly built oncology unit which provided chemotherapy and palliative care services in both admission and out-patient capacities to the referred patients living with cancer. It served as a main oncology referral for central and northern region of Malawi.

**Participants and sample size**

The study population included patients, caregivers and HCWs. The participants included those receiving treatment at the clinic. Eligible patients were those above the age of 18 years with histologically confirmed cancer disease regardless of type and stage of diagnosis. Caregivers included those caring for patients at the National Cancer Centre while HCWs were those working at the National Cancer Centre. All patients who did not give consent and critically ill...
at the time of interview were excluded from the study. Purposive sampling was used to select thirteen participants. This included four patients, four caregivers, four healthcare workers and one clinic supervisor/ ward in-charge.

**Data collection**

In-depth interviews (IDIs) were used to collect data and a semi-structured interview guide was used to collect the data. The contextual model of health-related quality of life theoretical framework was utilized in the study. It is a multidimensional, dynamic concept with physical, psychological and social components. It defined an individual's general perception of his/her physical and mental health by focusing on a disease and its treatment effects on other aspects of life. The guide therefore, included questions to explore individual level and systemic/facility level factors that may affect quality of life. Individual level factors include physical and psychological aspects which are associated with HRQOL. Before conducting IDIs, participants were given information sheet and informed consent form to read and make an informed decision to participate. All interviews were conducted in a private room provided by facility staff in-charge. Interviews for caregivers and patients were conducted in Chichewa while those for HCWs were conducted in English by a trained interviewer who was fluent in both English and Chichewa.

**Data analysis**

Demographic characteristics were summarized and presented descriptively. The audio-recordings were transcribed and translated into English by the interviewer and reviewed by the Principal Investigator (PI) for accuracy and completeness. A codebook was then developed through reading of 2 transcripts and identifying common themes and sub-themes. All transcripts were double coded by two authors (JCB and MT) and coding comparison was done. Interrater reliability for this study was set at 95% and any differences below 95% were discussed and consensus reached. We used the following predetermined themes: physical factors, psychological, social and healthcare system components of HRQOL.

**Ethical standards**

All methods were performed in accordance with the relevant guidelines and regulations and was approved by an appropriate ethics committee.

**Results**

**Study participants characteristics**

There were 13 participants in the study and most were females. Respondent categories included four patients, caregivers, healthcare workers and the single unit supervisor as presented in table 1.

**Table 1.** Sociodemographic characteristics of the study participants.
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Patients (n)</th>
<th>Caregiver (n)</th>
<th>Health worker (n)</th>
<th>Total (N)</th>
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<tr>
<td>Esophageal cancer</td>
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<td>1</td>
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<tr>
<td>Breast cancer</td>
<td>1</td>
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</table>

Emerging individual level themes perceived to determine quality of life

Knowledge of cancer diagnosis, reaction after diagnosis, experience with treatment, change on physical, psychological and social health, support received, benefits and challenges.

Knowledge about cancer diagnosis:

Knowledge of cancer disease encompassed patients’ and caregivers’ understanding about the cancer disease, potential benefits and side effects of the proposed therapy. In the current study, all four patients and three caregivers had full understanding of the nature of the disease they were dealing with. They were able to mention the type of cancer and organs affected. Similarly, they could narrate how a patient suffering from cancer could have a chance of cure from the disease given appropriate treatment in good time while also accepting the possibility of dying from the disease just like any other disease. One caregiver narrated:

“Cancer is a difficult disease. Like in our case, s/he started in 2019 and s/he seemed to recover then it resurfaced. It is a difficult disease because it causes many health problems. Sure, so the immunity is decreased, loss of appetite, body weakness, everything is affected” (Caregiver # 2). “She is suffering from cancer which is in the esophagus but it affects the lymph nodes.” (Caregiver # 3). Similarly, patients were well aware of their disease condition. Once patient said: “It is cancer of the nose. I don’t know the specific area but it affects the nodes around it. A person has hearing difficulties, can vomit blood from the mouth and nose. Its treatment is drugs, surgery or radiation.” (Patient # 4). Additionally, the patients knew that cancer was the disease which could be cured, it could recur and there was a chance of complete cure. One patient indicated: “I was told that cancer is a disease that can sometimes spread, sometimes it can stick on one place, sometimes you can recover and sometimes you can die.” (Patient # 4)

Physical health experiences following cancer diagnosis:

These were physical appearances and body changes due to cancer diagnosis; its treatment and they included following: weight loss, skin changes, body weakness, body scarring, vomiting and many others. In the current study, patients were experiencing pain, vomiting, weight loss, fatigue, swelling of body parts and anemia. One patient had said:
"It has drastically changed my physical health. For example, disability. I don't have one breast. Additionally, I feel strong pain in my veins and of course I have loss of weight. This is not my usual weight. Sometimes I even fail to take a bath on my own. I cannot wash clothes on my own to make it look clean. I rely on someone to do it for me. I have never experienced vomiting. I don't vomit. Yes. I feel numb on two of my fingers." (Patient # 1).

Another patient indicated unpredictability of body fitness due sudden changes of disease symptoms. "I cannot work as before because in most cases I am weak. For example, I can be fine in the morning but in the afternoon, I find that I am shivering and that means I am not going to do anything, I have to sleep. In terms of vomiting, I don't vomit but it has just changed my body like loss of weight." (Patient # 2). Caregivers also described physical challenges experienced by their patients. One caregiver said: "With the cancer disease, the patient is not in good condition. She cannot walk nor take a bath. It is a difficult situation. Even eating is a problem. She is selective in food uptake. The pain is so severe. The leg is swollen and the disease changed her/his quality of life." (Caregiver # 4).

**Psychological experiences following cancer diagnosis:**

These were emotional experiences by the patients, caregivers and families following a cancer diagnosis and these included: denial, anger, anxiety, distress, and depression among others. The immediate reaction by patients and caregivers was negative to the diagnosis. They were overtaken by disbelief, denial, fear and anxiety about the diagnosis because they perceived it as a disease associated with long period of suffering and that someone may not fully recover and return to normal function. One patient reported: "I was very disappointed. It was something that took me time to accept it. I had many questions like "what happened to me to suffer from cancer? Is it preventable or not so that I can tell my relative to take control measures so that s/he does not suffer from cancer." I was really disappointed and the diagnosis changed my life." (Patient # 1).

Another caregiver had similar perception about the cancer diagnosis:

"When I heard that it is cancer, it affected me badly. Considering her age, I was badly affected and this made me to fall sick because I am very close to her and she is very intelligent at school. So, thinking about length of the cancer treatment, I was badly affected because I thought that she would be affected in some areas of her education. So, I was affected so much." (Caregiver # 3).

The feeling of being hopeless was apparent from the patients: "My hope is limited because sometimes I lose hope that "maybe I am not going to recover, maybe I am going to die. With the pain that I am experiencing, maybe I will die by next month. So, I cancel all the long-term plans." (Patient # 1). These stages of emotional reaction to cancer diagnosis were expected reactions considering the deadliness of the disease however, such reaction could be therapeutic when coping with the disease 19.

**Acceptance to cancer diagnosis:**

It was apparent that both patients and caregivers required enough time to think-over the new disease situation. They needed time of reflection as evidenced by one patient indicating it took him a long period of time to accept the disease and re-adjust life expectations and future plans 19.

One patient said: "I accepted it. Of course, at the beginning I was in denial, I was wondering how this has happened but when I started receiving treatment, I accepted it." (Patient # 2). Similarly, one caregiver said: "I was concerned when I heard that she has cancer considering the severity of this disease. The person becomes weak, she cannot do her normal cores. So, I asked her "did you go early at the clinic?" She said "I went late". So, I was so worried. However, I believe with the treatment that she is receiving, she can get better." (Caregiver #3).

Additionally, another patient hinted on the positive transformation from being completely hopeless to a new level of self-belief following cancer treatment. The improvement in physical symptoms was key to gaining confidence of possible cure to the disease. This was what he said during the interview: "Mh... I can say that I have had lost hope "am I going to be, okay?" But currently, with the treatment that I am receiving, I have hope. I am able to differentiate because I was not able to do anything before but now, I am able to. I am hopeful that I am going to recover" (Patient # 2).

**Social life experiences following cancer disease:**

Patients living with cancer experience problems in various aspects of social life, such as family life, relationships with people around them, work, income, leisure activities, and relationships with healthcare providers 20. One patient indicated how much his work was affected and no longer being relied upon due to body weakness. His explanation was clear as follows:

"At community level, it changed very much because people depend on you that "she is able to buy us sugar, salt, fertilizer" but this disease changed so much that I am not able to do things like those. At work, they stopped relying on me regarding my position because of my condition. They just maintain me that "this one is a meter reader but they cannot rely on me much because I am not working most of the days. Even at home, the children were relying on me that "mother is going to wash for us but you find that a child is coming to school but there is no food while I am there. Things that were not happening before. They were finding everything done by me. Yeah, so things changed very much." (Patient # 1).

Patients struggled to do the chores that could support a living as before. They were not able to support their families and felt guilt about that experience. On top of failing to contribute to family needs, patients complained of failure to support themselves with usual activities due to disease severity. "For work, I stopped working because I cannot manage. I do business but I cannot travel long distances such as going to South Africa, Zambia or Mozambique. So, it changed my life because I have to wait until I recover." (Patient # 2). Due to protracted disease condition and avoidance of inviting several questions related
to their disease from friends, some patients resorted to self-isolation. This was observable by one caregiver who clearly indicated how social interaction has been affected by his patient during the period of suffering from cancer.

“The patient is very worried, he currently isolates but previously he was playing football, working on electronics but now few friends come to see him but previously he had so many friends. So, he is very worried. This patient is depressed up because he isolates and is discriminated. When the caregivers are away, it makes him feel more worried. So, his social life is compromised as compared to the past.” (Caregiver # 4).

**Support received from healthcare workers, families and friends:**

Participants shared the type of support they received from family, friends and the community which included material, spiritual and psychosocial support. One patient reported positive socio-economic support which she was getting from friends such as taking her to hospital during appointment schedules. They were able to contribute money for transport and other needs. “My relatives and friends have been supporting me in various ways. My fellow business women have been supporting me. They are the ones who have been driving me to the hospital here. They have been contributing money for transportation. They were supportive and the relatives took part.” (Patient # 3). Caregivers were being supportive to their patients. Providing daily care, encouraging and making sure prescription was followed and moral support in prayers. The continuous presence of caregivers was key to a feeling of being loved during the period of suffering, and this was vindicated by strong comments from them. One caregiver said:

“Firstly, when we knew it was cancer, we started telling her/him the issue of prayer. We started by telling her/him that “this is not the end of your life, this is a new life and for us to stay in this new life, we need to pray hard.” That is the first thing that we encourage her/him. the other thing is encouraging her/him the importance of consistent drug uptake and adherence. We encourage her/him so much to take drugs and when time to go to the clinic has come, we encourage her/him “you need to avail yourself at the clinic at this time.” We make sure s/he arrives at the clinic at the right time so that s/he receives drugs at the right time.” (Caregiver # 3)

**Emerging facility level themes perceived to determine quality of life:**

This included materials, human, and organizational resources affecting health systems’ ability to provide individualized/personalized care. Availability of resources such as drugs and supplies, availability of facility space and infrastructure, relationship with healthcare workers, experience with treatment, relationship with providers, satisfaction with care, facility organization, support from facility, barriers to QOL, things which needed to be changed at the health facility are some of the contributory determinants to quality of life.

**Drugs and supplies availability:**

Drugs and supplies were not always available at the facility. However, the patients and caregivers understood issues of supply chain problems and therefore their perception was positive. One patient indicated that although some drugs were out of stock, the management of the facility tried hard to find alternatives so that the service should not suffer.

“I can say that the availability of the drugs at the pharmacy is the same because if there is no Brufen, we find Panadol. If there is no Diclofenac, we find Tramadol. If one type is not available, the other type is available but they are all painkillers.” (Patient # 1)

**Facility space for service provision:**

There were mixed reactions by patients and caregivers in terms of space availability at the facility. Others would say it was spacious while others said there was no enough space for patients at the waiting area. Additionally, the perception could have been influenced by the socio-economic background where someone was coming from and hence being subjective. One patient said: “In terms of space, it is very good and you would wish to relocate from home to the hospital... [Chuckles]... because there are good beddings and the availability of food. In most cases, we leave the food because we say “we are full.” (Patient # 1). While the caregiver complained on how waiting space was not enough for them, it was clear participants had different receptions as shown here: “They sit here, there is space and sometimes when there are many people, they wait for someone to go inside and they sit on the chair because on Tuesdays there are many people.” (Caregiver # 1)

**Relationship with healthcare workers:**

Participants described the empathetic relationship that doctors and nurses provided. It was however noted that some staff were harsh. Information about cancer was provided accordingly. Patients responded positively by indicating that they were satisfied with service they received at the facility. The support staff such as watchmen and cleaners could speak politely and they were willing to support whenever necessary however it depended on how they had been approached.

“I can say that they listen attentively to our problem and they treat us based on our presentation of the problem. Okay, for example clinic aids and guards? With those ones, the relationship is there. For example, when we are new here, we first go there and they are able to escort us to the required place. even the clinic aides, when you are sitting at a place where they want to mop, they ask politely; can you move to the other side, I would like to mop.” They don’t shout or insult us.” (Patient # 1).

Sometimes, the perception depended on the personality of the healthcare worker on duty. Others were very friendly while others were harsh. It was narrated that some healthcare workers did not pay attention to their disease status however, only few of them had such personalities. One caregiver said:
“Our relationship with nurses is good but there are times when they are busy with other things instead of focusing on the patient. You find that they are playing on phone or chatting with friends, something that is not helpful. In terms of other staff, they are not helpful. For example, today when we were coming, we found them mopping. So, I was surprised “why mopping this time? Why can’t they come early and mop in good time?” So, they send you out so that you give them chance to mop. “Wait, they have gone to collect the drugs”, so these workers delay the processes.” (Caregiver # 4).

Satisfaction with cancer care:

This included patients’ and families’ expectations, preferences, and perceptions of quality of care, including appropriateness, coordination, access, and continuity/transition of care, followed by emotional support and physical comfort. All the participants specifically patients and caregivers said that they were satisfied with the care they received at the KCH cancer clinic. One patient defined satisfaction in terms of timely acquisition of prescribed treatment by the attending physician. “Satisfaction with the treatment is there because it consistently comes at the right time. So, on my part, everything is in order”. (Patient # 4). Another patient had similar comments. “I am satisfied because when we talk about the right time, we are considering that you went to the facility early and were diagnosed at the right time. In that way you can be assisted and it is possible but if you went there late, there is nothing that the doctor can do because they are not God.” (Patient # 1).

Generally, there was satisfaction with the service provision despite few delays in getting chemotherapy treatment. The delay in the perception of one caregiver was due to long distances healthcare workers would travel to pharmacy to get their supplies and it was taken positively. “We are satisfied although sometimes they delay because drugs are stored in pharmacy but we are not worried because we come here at the facility to get treatment.” (Caregiver # 1).

Facility organization:

The organization of the clinic was being described in terms of patient flow at the facility, demarcation of the consultation rooms, availability of admission rooms, record keeping, appointment dates for patients etc. This type of organization received mixed responses from participants. Most of the patients had indicated that the cancer clinic was well organized.

“I feel like the management of this facility has good organization. The indicators are on time management on part of healthcare workers and their cooperation. Yes, it is good because had it been that they come around 10 or eleven or they have conflicts with each other, we would say there are poor organization on part of management.” (Patient # 1).

One caregiver had also commented positively about time management by staff members to be good, however, there were certain lower cadres at the hospital which were slow at disbursing laboratory results:

“About the organization of this facility, we only complain the time when we are coming for results. When we come for sample collection, the providers are fast because they have many people on the queue and they make sure the assist them to go home in good time but when we come for results, the providers are slow and when we delay in receiving the results, we go to the doctor late and it means we delay in receiving the drugs. This takes much of our time and we leave late in the afternoon. So, I would recommend that those who give the results should be punctual so that we can go to the doctor in good time.” (Caregiver # 3).

However, some participants particularly healthcare workers were critical of the non-availability of some infrastructure such as blood bank as affecting organization of the facility since samples travel long distance. In the process, some samples go missing and thus affecting quality of care given to patients. “Ah... my comment on the clinic setup could be the clinic is not yet finished as you know. We don’t have our own theatre; we don’t have our own radiation room... and we also don’t have a laboratory. So, I feel that the setup is still in progress because we are lacking a lot of those facilities as I have said that on the laboratory thing, when we want to collect blood, platelets or other blood products, as well as when we want to send samples, we travel a long distance to the lab which KCH has.” (Healthcare worker #1).

Facilitators to improved quality of life:

The commitment and their attitudes towards the cancer patients were important benefits from the cancer clinic. Patients and caregivers were satisfied about the care which they were getting from the hospital in terms of reception, food provision at the facility under the Government support. They also expressed satisfaction on the willingness by healthcare workers to listen to their concerns. One patient said: "Ah... the benefits [Facilitators] are there because when we come, the providers are friendly. We are able to come and be given drugs and results. We also receive food. These are the good things that we experience" (Patient # 4). The other patient also added his comment to the service provision satisfaction as reported in the following narrative: “The benefits are that when we come here, the doctors are keen to assist the patients and that the facility is smart because if it is dirty, the caregivers contract diseases. So, this makes many people to come and access care from this facility.” (Caregiver # 2).

Barriers to improved quality of life:

These were problems or challenges which patients and their caregivers faced in their pursuit of obtaining cancer care. The barriers were categorized as individual, social, environmental and health systems factors. These included: drug and supplies shortage, inadequate human resource for health, lack of kitchen for caregivers, lack of radiotherapy services, lack of laboratory and pharmacy infrastructure specific for cancer center were some the obvious challenges as reported by patients and caregiver. One caregiver had narrated the following: unavailability of some drugs, long distance to the clinic, shortage of staff members. The quality of care was affected by missing of specimen samples due to long distances of travel to where they were being...
processed. There was wastage of precious time which could have been invested in running other hospital duties. “Even the samples themselves, sometimes they go missing and the patient does not receive on that day, the patient has to come on another day. All those things are affecting the quality of life of our patients. They move long distances to access theatre. It is time consuming, it is not good. Another thing is that we have to prepare our chemotherapy. So, the hood is very far away from our facility because we move from the cancer centre to a place near the pharmacy.” (Healthcare worker #1). Another barrier was described in terms of drug shortages at the facility which affected the quality of care given to patients. “Lack of medications is the main barrier because mostly, our patients are prescribed two drugs but you find that they are only given one drug, that is chemotherapy. Sometimes they can be prescribed maybe two drugs but you find that we don’t have both of them or they can be given one drug and that has an effect on the improvement of the patient. On the same medications, there are some patients who go to pharmacy to receive antiemetics or painkillers but you find that they don’t have and when they go home, they vomit but they don’t have any antiemetics. Later, their quality of life is affected and they end up coming back and being admitted in the hospital due to dehydration and the like. They even end up being admitted in the hospital because they have severe pain simply because they were not given the painkillers.” (Healthcare worker #1).

Similarly, lack of kitchen was reported by caregivers: “There is no kitchen at the cancer center. We cook outside there under gmelina trees and we are worried of being attacked by thugs.” (Caregiver #2). Another caregiver complained of transport problems from home during appointment schedules. One caregiver indicated the following: “The challenge is when we come here on our hard-earned transport which is expensive and difficult to find and we find that the doctor who was supposed to provide the care is not available.” (Caregiver # 4).

**Things to change for improved quality of care:**

These were challenges or problems which required to be addressed in order to improve the cancer service delivery. All participants including healthcare workers agreed that the cancer clinic should have its own surgeons, cancer specialist, radiation facility, pharmacy hood, laboratory, X-ray, blood bank. Availability of these service would shorten waiting time for patients while improving service delivery at the facility. One caregiver reported: “Yes, they are supposed to change. For instance, there should be a blood bank right here. Pharmacy, laboratory should be here. This is a big hospital and one should not be going out there to get services from the pharmacy or laboratory.” (Caregiver # 1). Another healthcare worker cemented the need for cancer center to have its own radiotherapy services because cancer treatment requires multiple treatment modalities.

“So, it’s important that we have our own theatre, our own surgeons, and not moving long distances. So, it would be better if the hood is right here at the cancer centre. The other thing is the radiation centre; we need to have a radiation centre here so that there should be different treatments. We should not only depend on chemotherapy because some cancers respond to radiotherapy” (Healthcare worker # 1).

The issue of having a pharmacy away from the cancer clinic was also mentioned by patients. The unavailability of specific chemotherapy drugs and pain killers was a big challenge in pain control.

“Things that are supposed to change at this facility... for instance, at the pharmacy, we don’t know how their procurement process is like but it would be helpful if they could have stock of all the required drugs because we experience strong pain. We cannot fall asleep unless we take a pain killer. So, if they can try their best, things can go well with us.” (Patient # 1).

Patients complained of lack of adequate cancer specialists at the facility, as such they were mostly been reviewed by general practitioners in most of the time. Some patients and caregivers were not comfortable with the arrangement and felt it was not ideal for their treatment. “The things that I feel should change at this facility, when the patient is seen by the general practitioners, after three months she should be seen by a specialist.” (Caregiver # 3).

**Discussion**

The aim of this study was to explore perceived factors associated with health-related quality of life among patients living with cancer. Table 1 indicated the sociodemographic characteristics of the respondents of the study. Two broad themes emerged which included the following: 1) Individual level factors (e.g., type of cancer disease, reaction after diagnosis, experience with treatment, change on physical, psychological and social health, support received, benefits and challenges) and 2) Facility level factors. The facility level factors included: availability of resources, experience with treatment, relationship with providers, satisfaction with care, facility organization, and barriers to QOL, things to change at facility. All the four categories of respondents acknowledged the importance of physical, psychological and social factors impacting the health-related quality of life among patients and their families.

In this study, both patients and caregivers had adequate understanding of the cancer disease in their narrative which implied that healthcare workers provided elaborate information to the extent that every family member involved from the client side were knowledgeable about the disease condition. This was an indication that effective communication between health providers and clients took place. Good communication between patients, family caregivers, and the healthcare team is very important in cancer care because it helps improve patients’ well-being and quality of life. Communicating about concerns and decision making is important during all phases of treatment and supportive care for cancer. A patient-centered communication approach needs to be developed to reduce the emotional distress to patients and their families following a cancer diagnosis. The results were also supported by the findings in Belgium and Italy where patients also provided good understanding of the disease condition they were going through.

Patients and their family caregivers received news of cancer diagnosis with strong reactions of disbelief, denial and shock. Similar reactions were also reported in other studies. Denial, anger, sadness and depression are common reactions to cancer diagnosis. Receipt of a cancer diagnosis is often deemed as bad news because it is widely regarded as synonymous to a death sentence. This is particularly so because cancer is a life threatening...
illness often associated with a lot of physical disability such as loss of body functions, change in physical appearance, disruption of family and personal life plans, recurrence or progression of the disease and high symptom burden.

Patients in the current study complained of pain, fatigue, weight loss, loss of usual daily activities as important physical challenges due to cancer and had negative impact on their quality of life. Similar findings were also reported in other studies. The feeling of hopelessness by patients and their caregivers to the cancer diagnosis was obvious in their narratives and impacted negatively to health-related quality of life. Socially, patients indicated social detachment being demonstrated by self-isolation from friends, stopped being relied upon at work or at home due to reduced functionality. In terms of psychosocial support, the patients spoke positively regarding the support which they were getting from their caregivers and from the facility. However, some were self-critical of the continued over-dependency on their caregivers which took away their autonomy and it was negatively impacting on their HRQOL. They felt by being dependent to their caregivers, they were troubling their caregivers. The role of the partner and wider support systems are well documented essential components of adaptation to disease and facilitating good HRQOL.

In terms of the systemic challenges, the National Cancer Center where the current study was conducted was a newly established unit still under construction as such there were no social amenities such as caregiver’s shelter and kitchen for caregivers. This was a challenge to caregivers because it implied walking long distances to the main hospital premises for food preparation and other daily needs. The management should consider expediting the construction of caregiver’s shelter at the cancer center.

Both the patients and caregivers, as presented in this study, underwent the process of acceptance to the diagnosis and adjusting to life and this process took time. Acceptance doesn’t mean that anyone is giving up. Acceptance allows you to take control of your life and it is a psychological indicator of the quality of adaptation to life with a disease. An important finding was that patients conceded to have been undergoing the re-adjustment process as a form of acceptance because on the contrary, denial had shown to lead into adverse effects such as delays in seeking medical help and noncompliance with treatment.

The study participants were critical on the erratic supply of chemotherapy drugs which implied frequent changing of drug regimens depending on which ones were available at the time of clinical review. This had the potential to negatively affect good quality of life. The experiences of frequent drug stock-outs was also shared by other disease programs in the Ministry of Health in Malawi and that management was engaging on long term recapitalization of the Central Medical Stores Trust (CMST) as the institution mandated for procurement of drugs and supplies for public hospitals. The cancer center was well organized and respondents were in cognizance that construction to facilitate the expansion of services (e.g., radiotherapy) was still underway. The facility had clear scheduling of appointments and this was highly commended by study participants.

Patients and their caregivers in this study showed satisfaction to the service provided at the facility which implied that the quality-of-service delivery met their expectation and needs. Patient satisfaction with cancer care is an important indicator of the quality of healthcare systems and it is a key determinant of HRQOL. Normally, satisfied patients are more likely to comply with treatment, continue their use of medical services, and maintain a good relationship with their healthcare workers.

The facilitators of improved QOL as described in this study such as the commitment and friendliness by staff to serve, provision of food under government support were important components to leverage on drug compliance by patients which could impact positively on quality of life. Simple kindness as demonstrated by staff members in this study, was instrumental to diffuse negative emotions that were associated with cancer diagnosis and treatment and might eventually help to improve patients’ outcomes. Similarly, the provision of meal rations at the facility was aimed at addressing nutritional concerns to patients. Nutrition is a central factor in oncology, influencing the response to, and recovery from cancer diagnosis.

The common barriers or challenges experienced by patients and their caregivers included long distances travelled to seek medical attention and drug unavailability. They were highlighted as barriers to improved quality of life and it was supported by other studies. High travel costs negatively influences stage of diagnosis, appropriate treatment and compliance, outcomes and quality of life among cancer patients. The non-availability of radiotherapy facilities was troubling considering that more than 50% of all cancer patients could benefit from radiotherapy services for treatment. Respondents recommended that cancer center should have their own radiotherapy unit, theatre, surgical oncologists, pharmacy, laboratory for improved access of services. During the conduct of the study, such services were shared with the main hospital premises, distant from cancer center.

**Strengths and limitations of the study**

These results were site specific and therefore there might be problems to generalize to wider settings. However, it is possible to make inferences from findings and explore these in the context of existing literature. There is also risk of biases by the researchers. Additionally, data collection could not be extended to Queen Elizabeth Central Hospital as initially planned in the approved protocol due to logistical challenges hence could not compare findings between the two major cancer clinics in Malawi. As such, these findings could not address the differences in quality of life among patients between the two facilities as previously reported by another study.

**Conclusion**

This study has highlighted the importance of physical, psychological, and social factors as key determinants affecting health-related quality of life among cancer patients and their caregivers at cancer center at Kamuzu Central Hospital in Malawi. The QOL challenges experienced by patients and their...
caregivers, implied that cancer care interventions should consider a holistic approach to cover for both physical and psychosocial needs in order to improve health-related quality of life among patients.

**Abbreviations**

**DALYs**: Disability Adjusted Life Years  
**HRQOL**: Health-Related Quality of Life  
**HCWs**: Health care workers  
**IDIs**: In-depth interviews  
**KCH**: Kamuzu Central Hospital  
**LMICs**: Low-and -Middle -Income Countries  
**NCC**: National Cancer Center  
**QOL**: Quality of Life  
**WHO**: World Health Organization

**Declarations**

**Ethics Approval and consent to participate**

The permission to conduct the study was sought from Kamuzu Central Hospital (KCH) and Queen Elizabeth Central Hospital (QECH). Ethics approval was sought from the Kamuzu University of Health Sciences Research Ethics Committee. Data collection followed informed written consent obtained from participants before enrolment. Participants names were kept anonymous by disguising all identifying names of participants during analysis.

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**Data availability statement**

All datasets generated and/or analyzed during the current study are not publicly available because the corresponding author has not defended his PhD studentship. He is also working on another manuscript; however, the data is available upon reasonable request to jonchiwanda@gmail.com.

**Competing interests**

None declared.

**Patient and public involvement**

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication**

Not required.

**Provenance and peer review**

Not commissioned; externally peer reviewed.

**Consent for publication**

Not applicable.

**Author's contribution**

JCB and ASM were involved in the conceptualization of the study protocol, data collection. JCB, MU and ASM revised the protocol. JCB, MT, & AB analyzed the data. JCB made first manuscript draft. MU, MT, AB and ASM revised the first draft. JCB, MU, MT, AB and ASM edited the manuscript. All authors read and approved the final manuscript.
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