

# Delays to Cancer Care, Exploring the Factors Associated with Barriers to Accessing Comprehensive Cancer Care in Eswatini: A Qualitative Study

Dlamaini Xolisile<sup>1</sup>, Hlophe Lomalanga<sup>1</sup>, Maseko Thokozani<sup>2</sup>, Mahlalela Nonhlanhla<sup>2</sup>, Mkhontfo Mandzisi<sup>2</sup>, Nhlabatsi Zanele<sup>2</sup>, Mabuza Nomxolisi<sup>2</sup>, Vambe Debrah<sup>3</sup>, Haumba Samson<sup>2</sup>

<sup>1</sup>Ministry of Health, Eswatini, Swaziland. <sup>2</sup>University Research Co.LLC (URC), Mbabane, Eswatini, Swaziland. <sup>3</sup>National TB Control Program, Eswatini, Swaziland.

## Abstract

**Background:** Cancer care in low-middle income countries is very poor. About 85% of preventable cancers such as cervical cancers are contributing factors to mortality rate which is 18 times higher in low middle-income countries. This is partly due to observed delays and underutilization of prevention, diagnosis, and treatment services in developing countries, and delays in seeking health care when symptoms start or inadequacy or lack of services. Similar trends in delays are observed in Eswatini, and this study was conducted to identify the causes of such delays in Eswatini. **Methods:** A qualitative phenomenological study was conducted among cancer survivors and health workers. Focused group discussions were conducted among the cancer survivors from all four regions in the country using a focus group discussion topic guide. The health workers were enrolled as key informants and face-to-face interviews were conducted using a key informant interview guide. The key informants were hospital managers such as Hospital Administrators, Hospital Matrons, and Hospital Senior Medical Officers from all major hospitals and health centres in the country. **Results:** The findings showed that causes of cancer delays were due to patient related delays which include fear of cancer diagnosis and denial that led to delay in seeking care; shock, disbelief, and fear at time of diagnosis which delayed use of treatment services. Part of the delays were due to health system related delays which include lack of knowledge by health care workers; inadequacy of infrastructure and skill for delivering cancer services in the health system; delays in being (properly) diagnosed and treated for cancer. **Conclusion:** Cancer care delays in Eswatini relate to both the patient and the health system. These findings should be using in developing strategies to improve cancer care in Eswatini and to replan cancer programs so that they meet the needs of cancer patients.

**Keywords:** Cancer survivors- cancer care delays- cancer services- cancer screening

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## Introduction

Cancer care in Low- Middle income countries (LMIC) is very poor. About 85% of preventable cancers such as cervical cancers are contributing factors to mortality rate which is 18 times higher in low middle-income countries. The epidemiology trends show an increasing rate yearly and that significantly affects the younger generation of less than 65 years of age [1]. In Eswatini,

cancer is the third leading cause of morbidity and mortality among non-communicable diseases, and over 30% increase of newly diagnosed cases between 2014 and 2015 was reported [2]. Cancer is therefore a major health problem for the country that needs urgent attention. According to WHO guidelines/standards cancer care begins at primary level which involves health promotion

## Corresponding Author:

Dr. Maseko Thokozani  
University Research Co.LLC (URC), Mbabane, Eswatini, Swaziland.  
Email: tsbb139099@gmail.com

and prevention (screening and vaccinations), followed by diagnosis and palliative care that plays a role in deciding the relevant treatment, hence reducing mortality rate. There is observed delays and underutilization of prevention, diagnosis and treatment services in developing countries [3], and some studies have related these observations to insufficient knowledge about cancer, limited or lack of access to available services, and delays in seeking health care when symptoms, inadequacy or lack of services [4].

In view of the highlighted issues, understanding the causes of delays in utilization of cancer services in Eswatini is necessary. Such findings can inform the health system and cancer programs of the gaps that exist in cancer care, from which strategies to strengthen cancer care services can be developed. This study was therefore conducted to identify the causes of delays in utilization of cancer services in Eswatini.

## Materials and Methods

### *Study Design and Population*

A qualitative phenomenological study was conducted among cancer survivors and health workers. Focused group discussions were conducted among the cancer survivors from all four regions in the country using a focus group discussion topic guide. The health workers were enrolled as key informants and face-to-face interviews were conducted using a key informant interview guide. The key informants were hospital managers such as Hospital Administrators, Hospital Matrons, and Hospital Senior Medical Officers from all major hospitals and health centres in the country. These hospitals were selected because as major regional hospitals, they offer some cancer related services.

### *Study Sampling*

#### a) Key informants

In each of the major hospitals and health centres, the senior management (Matron 1, Senior Medical Officer and Hospital Administrator) were purposively sampled for Key Informant Interviews.

#### b) Cancer Survivors

Purposive sampling was done to select cancer survivors. One set of participants were drawn from cancer support groups established by Eswatini Breast Cancer Network in all four regions of the country. From these participants, through snowballing, another set of cancer survivors were elicited from all regions. All were invited to focused group discussions (FDGs) in each region. A total of 4 FDGs in all the regions were conducted.

### *Data collection*

In this study qualitative data were collected, by a team of 16 well trained data collectors on qualitative data approaches and study tools. Key informants were met in hospitals and health centres individually, and the information sheet was read, and informed written consent was obtained. A key informant interview guide was used to conduct face-to-face interviews, and information collected was on employment history; availability of

cancer screening, diagnosis and treatment services in their facility; barriers to cancer services; and suggestions for improvement of health care systems. Cancer survivors, on the other hand, were invited to FDGs, and an FGD interview guide was used to guide the discussions. Each FGD had 8-10 participants, and socio-demographic information was not collected from survivors. Each participant signed a written informed consent individually before participating in the FGD. Topics for discussions during the FGD were perceptions about cancer as a disease, cancer screening, diagnosis and treatment, experienced challenges while undergoing cancer care in the health systems, and suggestions for improvement of cancer services.

### *Data Analysis*

Data were coded using Nvivo 12. Data-driven inductive, thematic approach was used to generate themes. This ensured that the research findings emerge from the frequent, dominant themes inherent in the raw data collected, as described in other studies [5]. A narrative approach was also used to elicit in-depth understanding of the individual participant's contexts in decisions regarding (delayed) use of health services. This was combined with constant comparison. Combining cross-case analysis and within-case analysis helped to maintain the contextual richness of individual experience, as described in other studies [6].

### *Ethical considerations*

Ethical clearance to conduct the study was obtained from the National Health Research Review Board of Eswatini (NHRRB). Permission to conduct the survey was sought from the Ministry of Health, the Ministry of Tinkhundla and Development as well as relevant community leaders and health facilities through a written correspondence. All participants were informed about their rights including the right to participate or not, right to respond or not to questions, and their right to withdraw from the study at any point when they felt so, without them suffering any disadvantage. Participants were given detailed information on the purpose, objectives processes that were to be followed throughout the study as well as information on confidentiality and privacy. Participants were given an opportunity to ask questions or seek clarity before being asked if they wanted to take part in the study. Written informed consent was obtained from willing participants.

## Results

The study sought to identify the causes of delay in utilization of cancer services. This information was gathered from both the key informants and cancer survivors. As may be seen in Table 1, 58.3% of the KIs were hospital matrons, and 66.7% of the key informants were females. It was also observed that 66.6% were from the nursing cadre, and 41.7% held a diploma level of professional training. The participants had been employed in the health sector between 5 and 35 years and have been in their current leadership/management position for

Table 1. Demographic Characteristics of Key Informants

Key informant	Sex	Designation	Years of employment	Years in current position	Level of education
K1	F	Matron	30	3	Diploma
K2	F	Matron	28	1.5	Diploma
K3	F	Matron	35	2	Diploma
K4	M	Acting Senior Medical Officer	8	2	Bachelor's Degree
K5	F	Matron	35	0.5	Diploma
K6	F	Medical Officer	9	2	Master's Degree
K7	M	Nursing Sister (Acting Matron)	27	9	Bachelor's Degree
K8	F	Matron	30	1	Diploma
K9	M	Medical Officer	16	8	Bachelor's Degree
K10	M	Matron	19	1.5	Master's Degree
K11	F	Administrator	5	5	Master's Degree
K12	F	Matron	35	7	Bachelor's Degree

between 0.5 and 9 years.

#### *Causes of delay in use of cancer services*

From the KIs and cancer survivors' perspective, causes of cancer delays can be characterised into two major categories, 1) patient related delays; 2) health system related delays. Patient-related delays were described in the following themes:

#### *Fear of diagnosis and denial resulted in delay in seeking care*

Fear of being diagnosed with cancer even when symptoms such as lumps in breasts, led to survivors not to seek prompt medical care. The delay to seek healthcare was a result of factors including denial, fear, or lack of knowledge on the need for frequent screening. The fear is related to perceptions that once someone is diagnosed with cancer, they will die. Here are some quotes that came from the discussions:

*I had doubt but at the same time I would ask myself, "What if?" The lump started small; as small as a peanut. It continued to grow but I was in denial because it wasn't painful. I was then triggered immediately when I saw that this thing was affecting my nerves. It started with my arm; it was painful. I would take the strongest pain killers. The pain persisted. I told my sister and she encouraged me to go hospital and check.*

*I wish doctors could always remind us to go for cervical cancer screening. Maybe I could be having another child by now had the doctor told me on time to screen for cervical cancer.*

*...when I was away for treatment, my community members had expectations about me that maybe I will come back sickly, lost weight or more like a ghost. What makes it worse is that before you go for a treatment, some relatives come to tell you that several individuals who went to South Africa for treatment couldn't come back alive. My husband used to tell me people who had died and I could tell him that he is killing me. I told him that*

*those are stories that I do not wish to know.*

*Cancer affects everyone because even Christians do mention that we pray for you that you survive in the name of Jesus yet back in our minds we know that this person is dying...In the community, everybody thinks that you are dying.*

The key informants also related that fear of cancer diagnosis affected people's use of cancer services. They related that the population associate cancer diagnosis with a death sentence, and as such are afraid of being diagnosed with cancer. During counselling or education sessions, patients voice worries about whether they were going to die after diagnosis with cancer, if they will be helped, and where they could get treatment. Here are quotes from some KIs:

*"Patients ask if are they going to die, and can anything be done? Family members usually ask if patient can get help," K4.*

*"They ask about where to get treatment, questions about the cancer clinic in Manzini and the drugs that are taken as treatment, dietary misconceptions, those sorts of things," K11.*

The delay is further worsened by family and community perceptive descriptions of cancer as a disease that always resulted in death. Asked what the reasons for the negative perceptions about cancer in families and communities could be, survivors attributed it to lack of accurate information about cancer, and there was a general feeling that males needed more focus from cancer awareness programs, as demonstrated by the caption from some members of the groups:

*The community is not aware or not educated about cancer. They consider a cancer patient as someone who is going to die at any time.*

*Information is lacking in the communities, if Government will be going back to communities for awareness and education, they should consider that men*

are the one who need more education on cancer:

#### *Shock, disbelief, and fear at time of diagnosis*

Since cancer is associated with death, narrating on their reaction to the diagnosis with cancer, the survivors stated that they were shocked and fearful that they were going to die. This was followed by disbelief to the extent that others sought second opinion from other practitioners. The fear led to several actions in trying to come to terms with the diagnosis, which delays their use of treatment services.

*The first day you are told that you have cancer, you become afraid. I first feared when I heard that another lady had cancer. I didn't even know her, but this prompted me to go for a check-up [...]. What comes first in the mind is that I will die, what about my child, etc. [...]. Even today, it feels like I should not know if someone is dead. This is because I feel like I will be next.*

*I am a grandmother of 68 years; I was diagnosed with cancer in 2004. When I went for a surgery, I cried because I was afraid. It felt like I was going to die.*

#### *Experiencing cancer as a slow poison that affected the body and social and marital relations*

It was observed from the experiences related by the cancer survivors that cancer affects the survivor's body and social and marital relations. It happens as a slow process with the development of the of the diseases. The survivors related that they felt not adequately supported by their families and friends which made it difficult for them to cope their condition. This creates some emotional distance between the survivor and the family or friends. Body changes affect sexual relationships of the patients and their spouses, and some of the changes lead to permanent loss of functionality. As the disease progresses, the survivors lose hope on the ability of the health care workers in managing the disease, which affects their trust and use of cancer care services. Here are some quotes from the discussions:

*Cancer is difficult to explain, I would directly link it to a slow poison. It eats you slowly and by the time you find that you have cancer, you also find that it has advanced.*

*This journey I had gone through started by longing for a second born child.... I sometimes feel liked my husband can leave me at any time because he wants another child. He can leave me because of negligence by my doctor... The doctor cannot say anything... It challenges you and affects one physically, mentally and socially; you see yourself losing your marriage. I kindly request that once you are diagnosed with any cancer, the husband or your partner is also asked to come to hospital for awareness, education and counselling. In South Africa, they do reach out to your partner or someone who is very close to you for support. I gave Sister Paul my husband's number. She phoned him and they talked lengthy. They talked about my condition and his fears. As much as we may see the negative things from our husbands, they are also hurt. He*

*was also destroyed because he also wanted to have a child but now, he couldn't have a child with me. As a patient you think that my husband will leave me because I can't satisfy him sexually and I can't give him a child. All these things are not easy. This is the journey that I had to walk.*

*... Some of patients who had gone for breast or cervical cancer treatment in South Africa, found that their husbands had re-wedded traditionally (tekaed) another wife just for three months of being away in South Africa. An unfortunate incidence for one man, his second wife was also diagnosed with cervical cancer. Sometimes you find that the virus is from men because they are uncircumcised then to us females it forms cancer.*

*There are challenges that we face when we go back home because when you have a husband and you have cervical cancer; the husband looks at you differently. He doesn't take care of you or support you.*

#### *Cancer patients lack psychosocial support*

The key informants also related that based on their experience working with cancer patients, these patients need psychological and spiritual support as well as love and care because cancer treatment has many side effects which affected the patients' coping with the disease. There was a consensus among the key informants that this support is not readily available for patients, which is usually coupled with lack financial support from their families. This lack of support affects the patients' ability to honour hospital visits and leads to lack of adherence to treatment. This is what some had to say:

*"Mostly patients need psychological and social support [...] Cancer may cause disability hence spiritual support is essential, also support from family," K1.*

*"Cancer patients need family support, care and love. Most cancer treatments are hard on patients, so they need the support. Patients with the support survive better than those that do not. Early stages of cancer are treatable, so patients need to be encouraged to have the will and patience to live and wait for the treatment so that the cancer does not advance to other stages," K5.*

#### *Health system delays related to lack of infrastructure and expertise*

Health system delays were observed in the following themes:

##### *Lack of knowledge by health care workers*

The survivors' experiences revealed that cancer patients' feel that some of the local doctors who attend to them are not knowledgeable about their conditions. This degrades the patients' trust in them and the health system, which affects their use of cancer services.

*The doctor at chemotherapy unit is not well conversant with these things. I don't expect that we can be attended by a doctor who doesn't know anything because the one that we have couldn't even write or spell "cup" until the sister came to rescue the doctor.*

*In . . . [one hospital], the doctor would ask you how*



*you feel and do not do physical check-ups. However, in South Africa we were treated for everything and the check-ups were done for the whole body ...and the doctor would see even hidden things that could not be felt...*

*Honestly, it also seems like our health care workers in Eswatini they lack information on cancer management.... I have a bad experience because I came back with a needle.... I went to hospital to request that they remove the needle, but they refused. I went to casualty and requested the health care workers to remove this needle and they responded to me and say that they will try. The port has killed so many Swazis because locally they do not know how to handle it.*

*I also have the port and I went to our hospital and requested health care workers to remove it because it causes a sharp pain.... Some of the nurses at one major hospital simply tells us that they do not know this port and they were never taught it from school.*

#### *Inadequacy of infrastructure and skill for delivering cancer services in the health system*

The key informants decried the health systems shortages such as lack of diagnostic supplies, infrastructure and expertise to diagnose and manage patients. Also cited was the long turnaround time for results and unclear referral mechanism which causes poor communication between referring and receiving facility. At provider level, lack of expertise was the main cited challenge or cause for delay in provision of cancer services.

*"Honestly speaking it has been a challenge for us, first the issue of diagnosis, some samples sent to the lab it takes months to get the result only to find that the cancer keeps on eating up the patients, so delay of the reports is key, some patients then die," K2.*

*"We lack working equipment, and Swazi cancer specialist be trained, we lack radio therapy," K8.*

*"Lack of skills in giving best health care to cancer patients, they not trained about cancer; they only know about midwifery. The lack of skills makes nurses create attitude barrier. Lack of human resource; we have a little number of HCWs because we have an HIV epidemic," K6.*

*"No clear referral network for the patients. No specialist for management of specific cancers," K9.*

*"[...] Also, when patients are referred to Phalala Fund the queue is too long to accommodate all of them so they are bound to suffer," K11.*

#### *Delays in being (properly) diagnosed and treated*

At the time of the diagnosis of the survivors, Eswatini was referring almost all patients to South Africa for confirmation of diagnosis and treatment through the Phalala Fund. Participants were asked about their experiences with diagnosis and treatment. Their responses indicate delays in diagnosis and treatment were a result

of lack of vigilance in screening which led to subsequent delay in referral for diagnostic services, as shown in some quotes below:

*I started by having chest pains and I went to hospital and got pain killers. The pains lessened but where there were the chest pains, it felt like there was an open wound which is not healing. I went back to hospital after 5 months and I reported that it feels like there is an open wound inside the chest. Doctors looked at me and said that I look healthy. I requested for an x-ray. The doctor said, 'you are fine, let me prescribe sharp pain tablets.' I insisted and requested for an x-ray. The doctor allowed me and sent me to x-ray. The doctor was shocked when I came back with my x-ray mentioning that I had been seeing a healthy person but dying inside. The doctor said that one of your lungs is invisible. It looks like it is in fluids and I was admitted. I was drained the fluids from the lungs and later got discharged. I went back to hospital and mentioned that after draining the fluids I couldn't sleep. Further check-ups were done and found that my lungs were in fluids again. Everybody wondered what caused this fluid accumulation. Then I requested for a full body check-up, then they advised that let us start by checking HIV and TB. I was negative for all those, then I was given TB treatment assuming that after draining the fluid will not come back. TB treatment made me worse and the drained fluid were taken to Lancet Lab for further investigations .*

*... In 2013 I went for check-ups. This time the doctor said that I have a cyst and I have to remove it. After the operation, I went to ask the doctor on how the operation went because I had a clear discharge. After a while I went back to the doctor and reported that now my discharge is as if I am on my monthly periods and I have to use sanitary towels. I was told that I must come back the following day to check this discharge. The following day I went to cervical screening unit and asked how things are done for one to get health services. I was given pamphlets to read and some forms to fill and I was told that I should come the following day for check-up because they take 15 people per day.... They told me the same day that my cervix has problems. They showed me pictures of my cervix in a computer. I could also see that things are bad then they walked me through cancer and the stages. I was told that I am on stage3. I went back to the doctor but at the same time I felt like I was blaming him. I couldn't believe it and I had trusted him as an expert. I only asked him that, how come? How can I have cancer when I have been coming to him every now and then but he never thought of cervical cancer or else told me to go check for cervical cancer? He also couldn't believe it because in 2013 I had checked. He asked me to come the following day so that he can also confirm the results. I came the following day and he took a biopsy and sent to Mbabane clinic for results. When the result was available, he confirmed that I have cervical cancer.*

For some cancer patients, the delay in seeking the right treatment was an outcome of confusion caused by

health workers advise or poor communication between the health care workers and the patients which keeps the patients unaware of their care or treatment plans, or a long que in the referral system, as captured by survivors below:

*Another lady was told by one of my sisters who is a nurse by profession not to do mastectomy. Luckily all of us (support group members) encouraged her and she is still surviving breast cancer. The problem is that when a trusted nurse is telling you not to undergo mastectomy, you become confused.*

*Mostly we experience extreme pains and when we go to hospital, we are always referred to chemotherapy unit... There is a language barrier between us and the doctor. The doctor speaks a different language that we do not understand even if we speak in English. Nurses cannot interpret either because they also do not understand the language that this doctor is speaking.*

*We are now being transferred locally to some private clinics. It is so unfortunate because we cannot see what is happening. We are made to wait for long hours and move from one room to another without getting help. We are told to go to national referral hospital for CT-scan, even in there we wait for 2 weeks without getting CT-scan results. I then decided to stay at home because I wasn't getting help instead, I wasted money on transport. They were asking us about how we got diagnosed with cancer; what did they do, what type of treatment we were getting, etc. We are patients, how could they be asking us about that?*

*I went to my doctor and started preparing for the processes of going to South Africa for treatment... I would continue checking in the hospital on how far I am getting closer to go to South Africa for treatment. I talked with matron and she told me that the queue is very long. I cried. I cried because I had been told that cancer spread, I thought that by the time I get treatment it would have spread and progressed to another stage.*

For some patients the delay in getting treatment was a result of government's failure to pay for the treatment in South Africa where they were referred. This is what one participant in the group had to say:

*I went to hospital in South Africa for treatment in September 2015, I stayed there for 3 weeks without getting any treatment. The doctor did some test and check-ups and said that everything is fine. I could start treatment that same day, but government haven't paid outstanding arrears.*

#### *Attitude of health care workers towards cancer patients*

The attitudes of health care workers can motivate the cancer patients while taking their medication. The survivors compared the attitude of health care workers in Eswatini to those in South Africa, and felt that due to their attitudes, they made it difficult for cancer patients to use services or even to survive cancer. The survivors attributed these attitudes to lack of knowledge about cancer management or poor communication between

health care workers in South Africa and Eswatini when the patient is referred back to Eswatini. These are some of the excerpts from the discussions:

*In South Africa, nurses' greetings are the ones which makes us feel way better as compared to our nurses in the country. They are unable to open the port for those who are using ports. When you have been diagnosed with cancer, you can live all the designated years to live on earth. However, when you go to hospital and the nurses find out that you were being treated in South Africa; they simply dig a grave for you. They don't care about you and you don't get help. The attitudes you get from health care workers, do not give you any hope and you simply accept that you are going to die.*

*It is important that the doctors communicate among themselves because we found that the doctors in the country, they do not know what was done and the treatment we were given. This is a challenge because to us it looks like there is no much love given to cancer patients. Honestly, they also seem like our health care workers in Eswatini lack information on cancer management.*

*Treatment and check-ups from South Africa are different from what we get in Eswatini... In South Africa when you feel down and when it seems like there is no hope, the sister would take us to an enclosed room and tell you that Jesus is alive and tells us good news reviving hope. Whereas in Eswatini the nurses would scold us and ask us why we came so late. So, this make us worse.*

Given the delays and experiences with diagnosis and treatment engagement, the survivors were asked to share their experience with cancer treatment, and most had negative experience with local health providers as shown by the quotes below:

*Than to being treated in Eswatini, we opt to stay at home and do not go to seek for treatment because we feel like we are not getting care. In South Africa, they were able to see if cancer was now spreading and they would do that fast, at an early stage. That is why we feel much better and treated but now we stay at home when we have a headache or any pains in the body because we will only get pain killers in the hospital.*

*We would appreciate if there is communication between doctors in South Africa and in Eswatini as well as patients. Some of us dropped treatment as soon as we were told that there is no money for Phalala. Since then some patients have been out of treatment.*

Having comorbid diseases or condition also made the cancer treatment experience an undesirable due to many side effects while others were concerned that they were not experiencing side effects which made them suspect meant the treatment could probably be not working for them. This is what one participant shared:

*While we were undergoing radiation, every Wednesday we would undergo chemotherapy. I would have a problem and I was considering myself as not getting treated because all those that I had come with were reporting symptoms like becoming weak, etc. but I remained the same. I went back to the doctor and mentioned that some of the patients I came with are experiencing different symptoms, is there something wrong with me? The doctor*

*told me that it depends on the condition that you were in when you came for treatment; some of the patients are weak because they are suffering from other diseases such as HIV/AIDS, diabetes, etc. The doctor further mentioned that I am lucky that I came with no other ailments.*

Both the key informants and the cancer survivors were asked what could be improved in the health sector to improve cancer services. The cancer survivors recommended provision of comprehensive services not just cancer care, exploration of cheaper ways to manage cancer patients than sending them to South Africa, and the importance of doing more research on cancer. Here are some quotes from the survivors:

*We could request that our Government at least give us 2 chances or appointments in a year so that we can obtain this full body check-up that we were used to getting in South Africa.*

*Our Government can also explore options of requesting one or two doctors from South Africa who would come to Eswatini once or twice a week. This may not be expensive compared to sending cancer patients to South Africa.*

*We do need Government intervention to research about cancer so that we may know even food that causes cancer, food that we need to eat so that the cancer cells do not grow or increase because we do not have knowledge and information about cancer.*

*At the lodge where we were all accommodated, we would sometimes go without breakfast, yet we were going to take treatment. It would happen that even in the evening, there would be no dinner provided. If it happens that one complains about this, we were told that we would not come back for treatment the next time...*

*We urge that government does a follow-up on how we are being treated and that the money that is being paid does it work. Matron would come to check on us and during those days, we would be treated nicely. We used to stay with BaTswanas and were always treated well.*

The key informants, on the other hand, stated the need to intensify public's knowledge about cancer, the need to decentralise care, the need to use money paid for specialist care in South Africa to establish and/or strengthen local services for cancer such as building infrastructure and training a pool of local experts. Participants also suggested that there must be clear and concise referral guidelines as well as IEC material, frequent training of HCWs about cancer and resources to carry out community mobilisation and campaigns around cancer which will include onsite cancer screening. They suggested that a simple screening tool (such as one used for TB screening) at primary health care facilities would make a big difference in terms early identification of those at risk and refer them for screening, early diagnosis and treatment if found to be having cancer. This according to them, would contribute positively to the reduction of premature death as a result of late diagnosis and treatment. This is what some had to say:

*"We need an improvement on IEC (information, education and communication) material as facilities do not have those for cancer. Machinery is also not enough for screening and do treatment of cancer. The human resource*

*is not trained specifically and extensively on cancer;" K4.*

*"National education on cancer on all media channels locally, clinics, communities. Mobile outreach for educating the public. Pamphlets offering contacts details and educating about cancer. Healthy diet advocacy," K7.*

*"We need to be provided with enough essential resources for the detection, educate, treatment of cancer. The cancer screening should be decentralized to all facilities however small in the country. Medication must also be distributed to all health facilities to reduce long queues to major health centers for cancer medication or the treatment of its symptoms," K12.*

## Discussion

The study sought to identify the causes that led to delays in utilization of cancer care services in Eswatini. The study found some factors related to accessibility of cancer services as contributors to delays in cancer diagnosis and treatment. These include the travel time from home to the facility, waiting time in the facility, and receiving all required services in one's nearest facility. These findings show that to reduce delays in cancer care, cancer services should be made available closer to the person's home through decentralisation of services and community-based screening for early detection and waiting times in health facilities should be reduced. In some studies [7], it was observed that waiting times affected access and use of health services, and other studies [8] recommended that, based on their findings, cancer services should be decentralised to improve cancer care. This study also found that while people may be adults, some of the delays are due to that decisions about use of health services or payments of such services rested with other family members. This is generally true in Swazi households where the family head (generally the male parent or the female parent in his absentia) makes most decisions for the household including health and financial decisions. These findings imply the need to involve all family members in each household to ensure uptake of cancer services. The role played by the family in cancer care was also described in other studies [9] who described the diagnosis of cancer as a family experience, hence the entire family should be involved to reduce delays in cancer care.

Other causes for delays, as related by cancer survivors and KIs, occur at screening, diagnosis and treatment level. The study found that being afraid to be diagnosed with cancer delayed one's decision to screen for cancer or to seek medical care, even if they saw typical symptoms. These fears were worsened by community and family perceptions of cancer as a disease that always results in death. These findings show the need for providing communities and families with accurate knowledge about cancer to allay such fears and encourage them to screen early for early detection and treatment which can improve cancer treatment outcomes. Delays in diagnosis is due to lack of knowledge about cancer by the public which leads to cancer screening delays or the lack of vigilance in



screening by HCWs. The study findings showed that some diagnostic tests for cancer suspects were done in South Africa which comes with long waits before the patients are sent to South Africa through Phalala Fund, which also comes with long turnaround time for results. This implies the need for Eswatini Government to find strategies to improve efficiencies in the Phalala Fund to reduce related delays. While in their studies [10, 11] patients did not have to go to another country for diagnosis, they also reported results turnaround time for cancer patients contributed to delayed diagnosis of cancer.

It was also observed in the study that cancer diagnosis comes as a shock to the newly diagnosed patient, and the patient becomes overwhelmed with disbelief and fear of dying. As cancer progresses, it affects the patient's personal life and slowly degrades one's social and marital relations such that one may lose social or family support in the process. This delays the patient's acceptance of cancer treatment. Other studies [9] reported that cancer diagnosis changes the patient and their family's lives, bringing an immense amount of stress, and very often the family suffers comparable or greater distress than the patient. Other studies reported that the family goes through different stages of adjusting to the disease, that is often marked by intense emotional reactions including anger, resentment, guilt, and adjustment pain, which may or may not lead to the acceptance of the disease [7,9]. Often the reaction is a result of guilt, self-blame, injustice and lack of comprehension [9]. This shows the importance of involving the patient's family through-out the continuum of cancer care so that they can act as a source of support to the patient, and them too be supported by HCWs to be able to cope with the diagnosis.

Delays in starting treatment were due to confusion of the patient caused by health workers' advise, or poor communication between the health care workers and the patients which keeps the patients unaware of their care or treatment plans. Similar findings have been reported in other studies [11,12] and suggest the need to strengthen clear communication between the HCW and the patients and that patients should be involved in their care. The study also showed that some cancer patients are referred to South Africa or local private hospitals for treatment through Phalala Fund which comes with a long que. Some delays were due to government's failure to pay for the treatment in South Africa where the patient is referred such that they wait for weeks in South Africa before they are started on treatment. The referral pathways and mechanisms between the facilities are also not clearly defined for both HCWs and patients which affects communication between the facilities and delays the patients' access to treatment services. These delays are unique to Eswatini health systems and have not been reported in other studies.

Some patients lack financial support which affects hospital visits and leads to lack of adherence to treatment. Some of the delays in screening or diagnosis or treatment are due to lack of cancer expertise locally. Patients feel they are being attended to by local doctors who are not knowledgeable compared to those in South Africa,

which creates attitudes barriers between the HCWs and the patients, and sometimes led patient to frustration and defaulting treatment. Sometimes local facilities lack diagnostic supplies, infrastructure and expertise to diagnose and manage patients. Shortage of supplies or lack of infrastructure has been reported in other studies as barriers to diagnosis and cancer care [13,14].

The factors associated to delays in cancer diagnosis and treatment are accessibility related, patient related, and health system related. Services accessibility related include travel time from home to the facility, waiting time in the facility, and receiving all required services in one's nearest facility. Patient related factors include lack of knowledge about cancer, being afraid to be diagnosed with cancer, decisions about use of health services or payments of such services rest with other family members, lack of financial support, lack of social and family support due to degradation in marital relationships secondary to cancer, and lack of trust in the ability of the HCWs to provide the necessary services. Health system related factors include lack of vigilance in screening by HCWs, delays related to being referred to South Africa for diagnosis or treatment due to inefficiencies at the Phalala Fund; long turnaround time for results; unclear referral systems between health facilities; lack or unclear communication between the HCWs and the patient; lack of cancer expertise locally; and lack of diagnostic supplies, infrastructure and expertise to diagnose and manage patients.

To address health system related delays, local HCWs should be trained on oncology so that the health system has the necessary expertise, reduce the need for referral to South Africa, and HCWs can win the trust of patients. Cancer screening quality assurance standards should be set and adhered to address screening vigilance issues. This can be done by have cancer care guidelines that relate to awareness, prevention, screening, diagnosis, referrals, and treatment services. The Phalala Fund needs to revise its operation procedures and standards, and continuous evaluation should be performed to identify bottlenecks and address inefficiencies. This will also address the turnaround time of results. Clear referral guidelines and mapping of referral pathways of patients locally and abroad is recommended to referrals related delays. HCWs can be engaged through retraining and workshops on communication skills and the methods of involving the patient in their care for better outcomes.

#### *Limitations of the study*

This study has its limitations. Data were collected through face-to-face interviews which could induce interviewer related bias in how they conduct the interviews, and the data could suffer recall bias in participants' responses. The study also conducted focus group discussions. In those discussions, the study had less control over the data produced; little control over the interaction between the participants; and study could not assure full confidentiality and anonymity as information was shared in the group. During data analysis of qualitative data, data analyst related bias when selecting themes could have been induced. To minimize the effects of these limitation



on the study findings, the data collectors were well trained on effective methods of conducting qualitative interviews to minimise interviewer induced biases. Moreover, in this study, a triangulated the data collected by using different data sources was used, and data were collected from various data sources to triangulate the collected data and minimise biases. During FGDs, the discussions were generally kept focused on the topic, and the importance of keeping the information confidential was explained to the participants at the beginning of the focus group discussion. There was a balancing act in the process of reducing qualitative data into codes and categories with the desire to maintain the unique richness of qualitative data from the experiences of the participants.

### Conflict of interest

The authors of this paper have no conflict of interest.

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### References

1. LaVigne AW, Triedman SA, Randall TC, Trimble EL, Viswanathan AN. Cervical cancer in low and middle income countries: Addressing barriers to radiotherapy delivery. *Gynecologic Oncology Reports*. 2017 Nov;22:16-20. <https://doi.org/10.1016/j.gore.2017.08.004>
2. Ministry of Health. Annual Non-Communicable Diseases (NCD) Program Report 2015. Strategic Information Department. 2015.
3. World Health Organisation, Guide to cancer early diagnosis, WHO, Editor. 2017: Geneva, Switzerland.
4. Tiwari V. Identifying the Factors Causing Delayed Presentation of Cancer Patients to a Government Medical College of Central India. *Journal of Clinical And Diagnostic Research*. 2015;. <https://doi.org/10.7860/jcdr/2015/15104.6512>
5. Thomas DR. A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*. 2006 06;27(2):237-246. <https://doi.org/10.1177/1098214005283748>
6. Ayres L, Kavanaugh K, Knaff KA. Within-Case and Across-Case Approaches to Qualitative Data Analysis. *Qualitative Health Research*. 2003 07;13(6):871-883. <https://doi.org/10.1177/1049732303013006008>
7. Ramachandran A, Snyder FR, Katz ML, Darnell JS, Dudley DJ, Patierno SR, Sanders MR, Valverde PA, Simon MA, Warren-Mears V, Battaglia TA. Barriers to health care contribute to delays in follow-up among women with abnormal cancer screening: Data from the Patient Navigation Research Program. *Cancer*. 2015 08 19;121(22):4016-4024. <https://doi.org/10.1002/cncr.29607>
8. Wells KJ, Lee J, Calcano ER, Meade CD, Rivera M, Fulp WJ, Roetzheim RG. A Cluster Randomized Trial Evaluating the Efficacy of Patient Navigation in Improving Quality of Diagnostic Care for Patients with Breast or Colorectal Cancer Abnormalities. *Cancer Epidemiology Biomarkers & Prevention*. 2012 Oct;21(10):1664-1672. <https://doi.org/10.1158/1055-9965.epi-12-0448>
9. Hendren S, Chin N, Fisher S, Winters P, Griggs J, Mohile S, Fiscella K. Patients' Barriers to Receipt of Cancer Care, and Factors Associated With Needing More Assistance From a Patient Navigator. *Journal of the National Medical Association*. 2011 07;103(8):701-710. [https://doi.org/10.1016/s0027-9684\(15\)30409-0](https://doi.org/10.1016/s0027-9684(15)30409-0)
10. Hoffman HJ, LaVerda NL, Young HA, Levine PH, Alexander LM, Brem R, Caicedo L, Eng-Wong J, Frederick W, Funderburk W, Huerta E, Swain S, Patierno SR. Patient Navigation Significantly Reduces Delays in Breast Cancer Diagnosis in the District of Columbia. *Cancer Epidemiology Biomarkers & Prevention*. 2012 Oct;21(10):1655-1663. <https://doi.org/10.1158/1055-9965.epi-12-0479>
11. Primeau SW, Freund KM, Ramachandran A, Bak SM, Heeren T, Chen CA, Morton S, Battaglia TA. Social Service Barriers Delay Care Among Women with Abnormal Cancer Screening. *Journal of General Internal Medicine*. 2013 Oct 03;29(1):169-175. <https://doi.org/10.1007/s11606-013-2615-x>
12. Tejada S, Darnell JS, Cho YI, Stolley MR, Markossian TW, Calhoun EA. Patient Barriers to Follow-Up Care for Breast and Cervical Cancer Abnormalities. *Journal of Women's Health*. 2013 06;22(6):507-517. <https://doi.org/10.1089/jwh.2012.3590>
13. Freitas AGQ, Weller M. Patient delays and system delays in breast cancer treatment in developed and developing countries. *Ciência & Saúde Coletiva*. 2015 Oct;20(10):3177-3189. <https://doi.org/10.1590/1413-812320152010.19692014>
14. Susko M, Wang CJ, Lazar AA, Kim S, Laffan A, Feng M, Ko A, Venook AP, Atreya CE, Van Loon K, Anwar M. Factors Impacting Differential Outcomes in the Definitive Radiation Treatment of Anal Cancer Between HIV-Positive and HIV-Negative Patients. *The Oncologist*. 2020 06 04;25(9):772-779. <https://doi.org/10.1634/theoncologist.2019-0824>



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