

# Challenges Faced by Cancer Patients During COVID 19 Pandemic in Harare, Zimbabwe: A Case of Harare Cancer Centre Clinic Patients' Perspectives.

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## Abstract

**Objective:** The study aimed to assess challenges faced by cancer patients during COVID 19 pandemic in Harare, Zimbabwe. It further established how the outlined challenges affected the cancer patients' health (physical, social, mental, spiritual wellbeing) from a patient's perspective.

**Methods:** This qualitative study employed case study research method. It targeted Cancer Association of Zimbabwe (Harare Cancer Centre Clinic) cancer patients seeking health services during the onset COVID 19 in Zimbabwe. A pilot tested interview guide with open ended questions was used to collect qualitative data from purposively selected five respondents using recorded telephone semi-structured in-depth interviews. Recorded data was transcribed verbatim, coded and analysed using the thematic-content and narrative analysis methods.

**Results:** Multiple challenges emanated from COVID 19 itself, resultant lockdown measures and the changes instituted at the cancer treatment institutions. Common challenges included mental health related challenges, transport, livelihood, medical related challenges and collapse of both formal and informal cancer support systems.

**Conclusion:** COVID 19 exacerbated cancer patients' challenges. Cancer care should be prioritized and be integrated with current efforts to control COVID 19 pandemic. The study recommended innovative patient centred platforms such as mobile based information update, social protection and improving home-based care for cancer patients. Review of national COVID 19 guidelines such as enabling operationalization of the "patient's exemption" from travel restrictions and curfew, revival of patients' support systems and having a separate cancer fund should be considered.

**Keywords:** Cancer; COVID 19; Patients, Treatment; Challenges; Harare; Zimbabwe; Sub-Saharan Africa

**Abbreviations:** WHO: World Health Organization, HSD: Health Services Department, CAZ: Cancer Association of Zimbabwe, AMTOs: Assisted Medical Treatment Orders

## Introduction

Zimbabwe records an average of 7500 new cancer cases every year. The total number of new cancer cases recorded

among Zimbabweans of all races in 2017 was 7 659 comprising 3270 (42.7%) males and 4 389 (57.3%) females. The most frequently occurring cancers among Zimbabweans



of all races in 2017 were cervix uteri (20%), prostate (10%), breast (8%), Kaposi sarcoma (KS) (5%), non-Hodgkin lymphoma (NHL) (5%), oesophagus (5%), liver (3%), colorectal (4%) and stomach (4%). The other cancers accounted for 36% of the registered malignancies [1]. In Harare City, a total of 2 558 (35.2%) malignant tumours consisting of 1 181 males (46.2%) and 1 377 (53.8%) females were registered in 2016.

The majority of cancer cases in Zimbabwe are diagnosed at advanced stage (3 and 4) resulting in difficulties in curing the cancers and increased cost of managing the cancers. The late-stage diagnosis is due to lack of correct information on cancer and high prevalence of myths and misconceptions with regards to cancer. Fear of the disease also result in the delay to seek medical attention at cancer treatment institutions. In 2015, 86% of all the staged cases (2418) were diagnosed at advanced stages. In the year 2016 about 87% of all the staged new cancer cases (3352) were diagnosed at advanced stages. In 2017, 83% of the staged cases (3366) were at stage 3 and 4 [1]. Cancer patients in Zimbabwe had a long history of facing challenges with regards to inaccessibility of cancer services due to both centralisation and high cost of services. Zimbabwe's macro-economic challenges over the years exacerbated inaccessibility of cancer care services.

The current COVID-19 pandemic worsened health situation in Zimbabwe resulting in 8,275 cases as of 25 October 2020. As of 11 December 2021, Zimbabwe had 165 002 confirmed COVID 19 cases, 129562 recoveries and 4735 deaths. Only 3 943 961 people have been vaccinated as of 11 December 2021, [2]. COVID 19 pandemic has disrupted normal business in all facets of life in both developing and developed countries. Even the strongest health systems in developed countries have witnessed the greatest test on their preparedness and capacity to handle pandemics of such great magnitude as COVID 19 in the history of humanity. However, no research has attempted to assess the impact of COVID 19 and the subsequent control measures to the cancer patients in Zimbabwe, at least from a cancer patients' perspective.

In as much as it is prudent for the health systems to put great attention on COVID 19, it remains imperative for the same

health systems to ensure that maximum care for other health conditions is maintained. In the cancer care continuum, there is need to assess the patients who are on ongoing treatment to find out whether the treatments sessions can be postponed or rescheduled without negative health and psychosocial effects to the patients. The rights of the cancer patients need to be prioritized hence the decision for cancer treatment institutions should be patient centred.

Research has shown that cancer patients have an increased risk of getting infected with COVID 19 [3]. The COVID 19 pandemic brought in lot of changes in the health fraternity as the health systems try to adjust themselves for the containment of COVID 19 which come at a time when the health system in Zimbabwe was facing a mired of challenges such as out of pocket health financing in the background of hyperinflation, shortage of drugs, centralization of cancer management services. This adjustment although necessary, have implications on cancer patients undergoing treatment such that if due consideration is not factored in, the process may result in unintended systems delays in the provision of cancer care. It is well established that delayed oncologic surgery, radiotherapy and chemotherapy may lead to disease progression and reduces the changes of treatment success and leading to worse survival outcomes [4].

[5] highlighted the incapacity of Zimbabwe to upscale COVID 19 testing let alone to consider the cancer patients during COVID 19 crisis. He argued that Zimbabwe needs to invest in better salaries and working conditions for its frontline health workers, and decisively deal with graft within its structures. Makoni, 2020 also hinted on the ill preparedness of Zimbabwe's health system, especially the public hospitals in confronting COVID 19[6] noted that during the onset of COVID 19 in Zimbabwe, oncology and specialist services at public hospitals were interrupted. The outpatient departments and elective surgical operations were stopped at the onset of the outbreak including for patients with cancers. Such a situation prompted this study, which seeks to find out the challenges faced by cancer patients during the onset of COVID 19 in Harare, Zimbabwe.

## Methodology

### Study design



The study was carried out in December 2020 in Harare, the capital city of Zimbabwe. The study target population were the cancer patients who intended to get at least any one form of cancer management services during the COVID 19 period starting from 17 of March 2020 when COVID 19 was declared a national disaster in Zimbabwe following its declaration as a global pandemic by the World health Organization (WHO) on the 11th of March 2020 [7]. The research team followed up on the clients who visited the Harare Cancer Centre Clinic at least once, in order to find out their experiences in navigating the cancer care referral system and during the COVID 19 period. The study used qualitative research approach, case study research design and employs telephone based, semi-structured in-depth interviews data collection method.

#### **Data collection and analysis**

The interview guide was developed through a consultative process and was pilot tested and revised. The study employed a purposive sampling procedure and collected data from five cancer patients (males and females with different cancer types) due the urgent nature of the study, scarce study resources and limited study time. The study data set consist of 20-40 minutes digitally recorded in-depth interviews. The verbatim transcribing of data helped maintaining the richness of data.

The data was analyzed using content, thematic and narrative methods of qualitative data analysis in a very systematic manner. The data was first organized (transcribing, translation, cleaning of data, data labelling). Data was coded and descriptive analysis was done by arranging the responses in categories (content analysis) and identifying recurrent themes (thematic analysis). Narrative analysis was employed by the researchers to try and present narratives of and experiences of selected patients during the COVID 19 period. Participant's follow-up and constant listening to the recorded interviews were done during the analysis stage.

#### **Research ethical considerations**

The study got approval from the Cancer Association of Zimbabwe board. The study adhered to research ethics protocols including, informed consent, confidentiality, protection of privacy and, protection against harm. Verbal

consent was sought from the participant through phone calls, the researchers provided full information about the research and that the participants were free to withdraw from the study at any point in time. Respondents were fully informed about the procedures involved in the research. Anonymity of the participants and confidentiality was also assured throughout the research process. The data was handled in a confidential manner in line with the Cancer Association of Zimbabwe's operational research guidelines. Names of patients were omitted during data collection, analysis and presentation; instead pseudo names were used. Thus, this research adheres not only to research ethics but also to both the national COVID 19 guidelines [7] and the Cancer Association of Zimbabwe' workplace COVID 19 control measures.

#### **Minimising harm and maximising benefits**

The research ethical requirement of minimising harm and maximising benefits [8] was also considered in this research. The research tools were submitted to Cancer Association of Zimbabwe (CAZ), Health Services Department (HSD) for verification in order to minimise harm. Moreover, upon request of the study team, the Cancer Association of Zimbabwe provided free counselling to any research participant who needed the service in order to mitigate on any possible harm of the research. The benefits of the research include the utilisation of the research findings by the Cancer Association of Zimbabwe to improve and advocate for improved cancer service delivery during the current COVID 19 situation. The study findings were officially shared with the Ministry of Health and Child Care and other line institutions which provide services for cancer patients in order to ultimately improve general cancer care service delivery, during COVID 19, in the whole cancer care continuum.

#### **Reliability and validation of results**

The study team employed measures to ensure reliability of the results. Firstly, the use of telephone-based recordings was done to ensure that the researchers listen to the digital data many times during the data analysis stage. This minimised errors during verbatim transcribing process. Secondly, the data collection tool was designed and electronically shared among a panel of experts and patient volunteers whose feed-



back was incorporated in the final tool which was further pilot tested. Thirdly, the results were shared with volunteer expert cancer survivors, volunteer cancer patients and cancer stakeholders including cancer care institutions for validation. Internal peer debriefing and support specifically with the Cancer Centre clinic staff was helpful in identifying and rectifying biases. Finally, respondent checking of selected themes and interpretations was done within twenty-four (24) days after data collection for selected participants to verify and validate themes, data portions and some interpretations. This was done to maintain the patient centeredness of responses, interpretations, explanations and quotations and minimise researchers' bias.

## Results

### Demographic and socio-economic characteristics of the respondents

The respondents had varied demographic and socioeconomic characteristics which explain the varied nature and richness of the qualitative data collected in this study. These demographic and socioeconomic characteristics are intricately related to the ultimate challenges faced by the cancer patients. As can be deduced from **Table 1** below, all the respondents had no medical insurance to cover for their medical expenses and the majority (4) were either unemployed or self-employed mainly as vendors). The majority of the cancers were diagnosed at advanced stage (stage 3) signalling the need for continued palliative care for the patients. **Table 1** below shows the demographic and socioeconomic characteristics of the study respondents.

### Presentation of emerging recurrent themes

The emerging recurrent themes include mental health related problems, COVID 19 induced operational adjustments and other operational challenges at cancer treatment institutions, livelihood challenges for the patients and family, medication related challenges and COVID 19 induced paralysis of formal and informal community and workplace cancer support systems

#### Mental health related problems

Participants experienced some kind of emotional and psychological distress due to COVID 19 and changes on treatment schedules at treatment institutions. Psychological

distress emanated from constant worry over both their perceived increased risk to COVID 19 infection and the adjustments made at health institutions. All respondents suffered the traumatic experience of living with cancer in the light of a low resourced health delivery system as postponement of their treatment schedule without notice left them without any hope. No respondents reported stigmatization and discrimination in the society that they live but rather respondents concurred that the community was very understating and at time very supportive. However, stigmatization and marginalization at workplace was reported.

“I was forced to come to work despite the fact that I was under cancer treatment hence more susceptible to COVID 19. The supervisors said there was nothing special about cancer”, “No workmate visited me at hospital or at home”, “At our workplace there is a canteen, and I could not eat food from the canteen because it would lead me to a running stomach (diarrhoea) since I was under cancer treatment (chemotherapy). I had to bring my food from home and workmates, due to lack of knowledge, could stigmatize me, not knowing that changes in diet are common and necessary for cancer patients undergoing treatment”.

One participant (Ms.C.G.) who was receiving treatment at a private institution concurred with others that postponement of scheduled treatment led to psychological distress. She said, “These adjustments affected me because I was worried about the delay to complete treatment since I have an advanced aggressive cancer”. Receiving chemotherapy in a ward where cancer patients could talk to each other was reportedly very helpful to the mental health of the patient's undergoing treatment. COVID 19 resulted in a situation where patients had to receive chemotherapy while in separate room in order to contain COVID 19. One participant said “I was used to receive my chemotherapy while talking to other patients, supporting each other, and sharing stories, this was very fulfilling to me but during COVID 19 I had to receive chemotherapy while in a separate room. I felt very lonely and missed my friends I used to talk to in the chemotherapy ward”. Thus, isolation due to fear of the high risk of contracting COVID 19 exacerbates psychological and



emotional turmoil.

**Table 1:** Demographic and selected socio-economic characteristics of the respondents

Demographic and socio-economic characteristics of the respondents					
Demographic and Socio-economic variables	Study Respondents				
	Respondent 1 (Mr. T.C.)	Respondent 2 (Ms. C.B.)	Respondent 3 (Mr. R.C.)	Respondent 4 (Ms. A.G.)	Respondent 5 (Ms C.G.)
Age (years)	38	58	47	69	34
Gender	Male	Female	Male	Female	Female
Marital status	Married	Windowed	Married (second wife)	Divorced	Single
Number of Children	03	04	03	03	0
Religion	Christianity	Christianity (apostolic)	Christianity (apostolic)	Christianity (protestant)	Christianity
Highest level of education	Secondary (form 4)	Primary (grade 5)	Secondary (form 4)	Standard 5	Master's degree (MBA*)
Employment status	Self-employed (builder)	Self-employed (vendedor)	Unemployed	Self-employed (Vendor)	Employed (NGO**)
Main Source of Income for cancer treatment	Well Wishers	Support from children	Well-wishers, (mainly church)	Support from children	Self and Donations
Place of Residence	Rural	Urban (high density)	Urban (high density)	Urban (high density)	Urban (middle density)
Type of cancer	Colon	Breast	Skin	Breast	Colon
Cancer stage at diagnosis	Unknown	3	3	1	3
Cancer treatment institution	Public institution	Public institution	Public institution	Public institution	Private institution
Medical insurance	No insurance	No insurance	No insurance	No insurance	No insurance

\* (MBA) Masters in Business Administration  
 \*\* (NGO) - Non-Governmental Organisation

The psychological distress was also mostly emanating from failure to secure basic needs such as food, transport, medical fees, and homebased care kits during the COVID 19 period. There was a mixture of anger, fear, and frustration among the respondents who could not access cancer treatment services during the lockdown especially among those whose treatments sessions scheduled before lock down was promulgated were postponed. Postponement of booked treatment resulted in emotional turmoil of the patients. Worse still those who only noticed that treatment have been postponed after arrival at the public treatment institution. One respondent living with colon cancer (Mr.T.C.) reported psychological challenges in accepting to live with a stoma

bag. He reiterated that:

“I am a colon cancer patient, and I was inserted with a stoma bag just before the COVID 19 induced national lock down experienced problems in accepting the new condition of passing stool through the stoma. I needed counselling and assistance about this situation, but I could not visit any health institution for counselling and support as I would have done if there were no COVID 19 induced national lock down. I felt very lonely and hopeless at home”

“I was very worried about staying alone at home. My friends and relatives, at times phoned me saying they would have visited me if it was not COVID 19 travel restrictions” Thus, loneliness was a challenge impacting negatively of the health



of the patients.

The national COVID 19 updates sent through mobile phones by the Department of Civil protection without an option to unsubscribe were reportedly causing anxiety on cancer patients who were already aware of their increased risk of COVID 19 infection. One female participant who had colon cancer reiterated how the mobile phone COVID 19 deaths news updates disturbed her emotionally since she was already aware of her high vulnerability to COVID 19 infection (In Zimbabwe the COVID 19 cases and deaths updates were sent to individual mobile phones on a daily basis, by the Department of Civil Protection (COVID19ZIM) without any option for an individual to unsubscribe, if he/she feels uncomfortable about the death updates).

“I got very worried about the information on increasing COVID 19 deaths from national COVID 19 mobile phone update platforms since I was fully aware of my underlying condition (Cancer)”

“Information on COVID 19 deaths was scary and as a result I was at high alert of COVID 19 infection, and I decided to do home-based remedies such as inhaling lemon steam”

#### **COVID 19 induced operational adjustments and other operational challenges at cancer treatment centres**

It emerged from the study that all cancer treatment institutions (both private and public) instituted some adjustments to their daily operations during the onset of COVID 19 in Zimbabwe. One participant noticed the delays that were associated with using one smaller gate at one of the public institutions. This was necessitated by the need to make sure that all visitors are recorded, sanitized and screened for temperature before entry. Respondents were asked to rate the performance of their specific treatment centre before and during COVID 19. The rating was done on a scale of 1 (minimum) to 10 (maximum score) and the ratings are presented in Table 2 below:

All respondents were in one way or the other affected by the changes at the treatment centres particularly at public health institutions. Ms.C.B. pointed out that “during the COVID 19 induced lockdown there were no doctors at the treatment centre” She rated the institution’s performance (on a scale of 1 to 10) 7/10 before lockdown and this performance declined to 4/10 during COVID induced lockdown in April 2020 as

shown in table 2 above. It is clear from the ratings presented in table 2 that the perceived performance ratings of public institutions were low than private institutions and it declined drastically during the COVID 19 period. Mr.T.C. said “I started chemotherapy in March 2020 and was stopped in April and resumed in June 2020. The problem is that I was only told about the postponement of my booked chemotherapy session when I arrived at the treatment centre after struggling to get transport and passing through the roadblocks”

#### **Livelihood challenges for the patients and family.**

Livelihood challenges during the COVID 19 period were commonly reported by the study participants. The most common challenges include, loss of income, shortage of food, need for monthly rentals and school’s fees for the children. The COVID 19 induced lockdown impacted negatively on the income of the respondents. It is clear from the study that the majority of respondents depend on self-employment, mostly unregistered vending. This source of income was impacted negatively by the COVID 19 induced lockdown measures. Respondents were also asked about their main source of income to settle the treatment costs. It emerged that all of them had no medical insurance at all and were depending on family members, children, church and community members. All these support systems were undoubtedly impacted negatively by the lockdown measures. Some respondents could not get basic needs such as food. Ms.A.G. aged 69 years said, “I don’t have a husband; I’m also diabetic so I always run out of basic food commodities at home”. Mr. T.C. said “At times, I run out of food because I am no longer fit to continue with my self-employed work as a builder since the time I was inserted the colostomy bag. I no longer afford school fees for my child who is in form 3 at a local school and I am very worried about the future on my child”. Mr. R.C said. “I am the breadwinner so cancer has disabled me such that I can’t provide for my family. I now depend on assistance from well-wishers so at times I run out of food and clothes for myself and family. Well-wishers who used to assist us, particularly the church can no longer afford due to the lockdown measures since most people are not going to work so in as much as they may want to assist, they can’t”. These extracts of the respondents’ narratives revealed



livelihood challenges faced by cancer patients during COVID 19.

**Table 2:** Institution performance rating before and during COVID 19 as perceived by cancer patients

**Table 2: Institution performance rating before and during COVID 19 (scale of 1/10)**

	Type of institution	Perceived rating (Scale: 1/10)		Respondent's comments (narratives, explanations for the perceived rating)
		Before COVID 19	During COVID 19	
<b>Respondent 1 (Mr. T.C.)</b>	Public	07/10	03/10	"Requiring cancer treatment during COVID 19 was a misfortune"
<b>Respondent 2 (Ms. C.B.)</b>	Public	07/10	04/10	"There were no doctors (due to doctors' strike <sup>†</sup> ) when I needed treatment. This forced us to go to private practice. However, the situation has improved now (December 2020)", "postponement of scheduled treatment was not informed in time"
<b>Respondent 3 (Mr. R.C.)</b>	Public	04/10	0.5/10	"I used to get paracetamol, drip, and other tablets after my chemotherapy. I now have to look for the tablets from a private pharmacy with double the amount I used to pay at the public institution, and I could pay in RTGS <sup>‡</sup> unlike in private pharmacies which need USD <sup>§</sup> and if they accept RTGS their exchange rate is higher than the Reserve bank official rate. I wish if public institution become a one stop centre for all cancer related medication."
<b>Respondent 4 (Ms. A.G.)</b>	Public	5/10	2/10	"If it was not COVID19 the -- treatment centre is OK" <sup>¶</sup>
<b>Respondent 5 (Ms. C.G.)</b>	Private	8/10	09/10	"The institution updated me in time of any possible changes through phone calls. Any delay in treatment was not because of the institution but due to days of delivery of medication from outside pharmacies"

<sup>†</sup>Health officials went on strike during the early onset of COVID 19 in the year 2020

<sup>‡</sup>RTGS: Real Transfer Gross Settlement (one of Zimbabwe's official currency, in a multi-currency system during the transitional period)

<sup>§</sup>USD/\$: United states of America Dollars (medication was charged in foreign currency as pharmacies chose stable currency)

<sup>¶</sup>"OK": Good

### Medication related challenges

It emerged from this study that respondents experienced challenges related to high cost and availability of cancer related medication. Some of the treatment sessions were skipped because of failure by patients to secure the money required to buy the medication. Even those receiving treatment at public institutions at times had to secure medication from private pharmacies since the pharmacies at these public institution usually run out cancer related medication. Ms.A.G. whose breast was removed due to breast cancer said, "Medication is very expensive, I only get assisted by the Cancer Association of Zimbabwe (CAZ) once (free medical support), but these days CAZ staff always say they

no longer have the medication in stock". "The cost of medication could go as high as United States Dollars (US\$) 180.00 in private pharmacies." Mr.T.C. said "I always run out of colostomy bags because they are very expensive, and they are not readily available"

Treatment postponement due to cost of medication was common among the respondents. Ms. C.B. said that "My treatment was postponed but the postponement was not necessitated by the lock down measures or COVID 19 but by my failure to secure the medication. This is because; although the medication was administered at a public institution, I had to go to the private pharmacies to buy the medication. The cost that I had to bear included US\$ 180.00 for cancer



medication, US\$ 40.00 for blood, US\$ 35.00 for tests and then RTGSS\$ 130.00 for administration of the medication at public cancer treatment institution. During the COVID 19 necessitated lockdown, I could not get the money because those who used to assist me could not secure the money since they were not going to work.” Mr.R.C’s treatment was postponed again due to high cost of medication. He said “I had the exemption letter to go for treatment during COVID 19 but I could not secure the money needed for medication. I needed to raise USD\$ 60.00. I used to get assistance from the church but during COVID 19 I could not get any assistance so I could not go for my monthly treatment requirements” Ms.C.G. who was receiving treatment in the private sector said “Even after payment delivery of medication delayed during the lockdown period. Some pharmacies were running out of stock”

#### **COVID 19 induced paralysis of formal and informal community and workplace cancer support systems**

Patient support systems help patients to cope with the challenges that they face. The study revealed that some support systems were highly compromised during the COVID 19 such that respondents experienced a number of challenges. All the respondents were not covered by medical insurance in any way. Respondents pointed out that they could not get financial, medical and emotional support during COVID 19 period. It emerged that the majority of the patients’ main source of income was from informal sources such as unregistered vending and undoubtedly COVID 19 induced lockdown measure impacted negatively on these informal operations. Old age public support system at public institutions was at least helpful. One participant was not paying at public institution when admitted for the administration of drugs because of old age. Ms AG. Said “I am happy that at a public hospital, I don’t pay admission fee because of my old age”. Ms AG went on to say “Despite the old age assistance at public hospital, medication is very expensive at the private pharmacies.” The old age assistance only apply to patients aged 65 years and above at public institutions only.

Cancer patients’ informal support systems were reportedly compromised. Ms.C.G. said due to COVID 19 she could not

get emotional support from other cancer patients during treatment at the private hospital because the new arrangement was that patients no longer come in numbers but they have to be booked so that they don’t meet and mix at the institution. Despite this being a necessary arrangement in line with Zimbabwe’s current COVID 19 regulations it deprived Ms C.G. the emotional support she used to get from other patients. Ms. C.G. working in the private sector with highly educated staff members went on to say she could not receive any form of support from her workplace. They could not even visit her at home or hospital but instead she faced stigma and discrimination at a workplace.

Even formal support systems were compromised, for example, one participant reiterated that Cancer Association of Zimbabwe’s medical support for cancer patients could not assist with drugs, since they were not in stock. Informal support system for respondents was compromised as well. Mr.R.C. pointed out that “although the lockdown was necessary, its promulgation resulted in me failing to get assistance from well-wishers and church that used to assist me to pay for my monthly treatment requirements”

Mr.T.C. said “My relatives used to help me to pay school fees for my child who is in form three (3) but due to the lockdown they could not assist since they are self-employed”. He went on to say “Well-wishers are finding it difficult to assist us because there is too much for them since they are not going to work during COVID 19 lockdown”. Ms.A.G was afraid soon after cancer diagnosis but latter she received counselling from a pastor and accepted her condition. During COVID 19 period she could not access the pastor’s counselling sessions since the pastor and his wife could not physically visit her and at times not calling. Thus, both formal and informal cancer support systems were paralyzed due to COVID 19.

#### **Transport problem and lockdown travel restrictions related challenges**

One participant (Ms.C.G.) indicated that April 2020 lockdown commenced when she was almost about to complete her cancer treatment sessions at a private cancer treatment institution. Although she was using private transport, she experienced challenges on her way to the private hospital. She said, “There were five road blocks from





my home area to the treatment centre, at one roadblock I was had to turn back since I could not be allowed to pass, I finally used another route to go to the treatment centre” Ms. A.G. said “There was no transport and at times I had to walk on foot for a long distance. There were no public buses from town to the treatment centre and at times I have to pay for taxis in United States of America Dollars. After the treatment I had to get a taxi because my condition would not allow walking and waiting for public transport”

Mr.T.C. “During the lock down period I faced transport problem to the treatment centre. I had to wait in a long queue for ZUPCO (Zimbabwe United Passenger Company - with cheaper subsidised fares) since I was denied preference to board the bus despite my condition. At one point I was denied entry at roadblock by the security agents and when I explained to them, they then allowed me to pass through, but they could not allow my caregiver to go with me. Another challenge is that at roadblocks during the lockdown, security agents wanted everyone to disembark the bus and queue outside along the bus holding their letters; they could not allow anyone to remain in the bus except ZUPCO staff. This means that I had to disembark and get inside the bus many times (about six times/at 6 checkpoints) for me to arrive at the treatment centre yet my medical condition was poor.”

## Discussion

Cancer treatment institutions (public and private) made some adjustments which negatively impacted on accessibility of cancer services as they warmed up for the onset of COVID 19 in Zimbabwe. The negative impact of these COVID 19 induced adjustments even in well-resourced health systems is documented. [3] noted that the adjustments may lead to deprivation of resources and crippling of access to other healthcare services as health systems try to adjust and responds to the COVID 19 effectively. For example, it has been estimated that since January 2020, more than 30 000 medical workers travelled from areas around Wuhan-to-Wuhan city to help manage COVID-19 patients and contain the outbreak leading to a decrease in the number of doctors and other health care professionals in source regions [3].

Patients reportedly faced a number of mental health related challenges due to COVID 19 itself, the resultant control

measures such as nation lockdown and the operational adjustments instituted at the treatment centers. They experienced stress due to isolation, fear due heightened perceived risk of COVID 19 infection and anxiety emanating from postponement of treatment schedules. Similarly, [9] writing about India, noted that the COVID-19 pandemic and associated physical isolation practices are likely to result in a range of mental health and psychosocial challenges. [10] also noted the high magnitude of mental health and psychosocial challenges in the COVID-19 pandemic.

The mental health and psychosocial challenges experienced by the respondents in this study were varied and emanated from not only the adjustments instituted by the cancer treatment centers but also from the high vulnerability (both perceived and real) of cancer patients to COVID 19 infection. [11] highlighted that patient with cancer are considered more susceptible to SARS-CoV-2 infection than individuals without cancer not only because of age, given that cancer incidence is strongly linked to advancing age, but also because of the high prevalence of cancer risk factors also associated with COVID-19. [12] also maintained that cancer patients are more likely to develop COVID-19, and cancer is associated with a more severe course of the COVID-19 disease. Realization of the vulnerability of cancer patients has been documented as resulting in psychological challenges such as fear, anxiety, stress and depression among cancer patients [13].

Currently, the vulnerability of cancer patients to COVID 19 infection is well documented and high deaths of COVID 19 have been linked to high prevalence of non-Communicable diseases such as cancer. In his speech during the online 2021 World Cancer Day (WCD) commemoration organized by the [14] the Minister of Health and Child Care, Honourable, Vice President Chiwenga, reiterated that Zimbabwe COVID 19 mortality data trends has shown that the likelihood of dying from COVID 19 was higher among those with non-Communicable diseases such as Cancer, [15]. This intricate relationship between cancer and COVID 19 infection cause a lot of anxiety on the cancer patients as noted in this study.

The study revealed that, cancer patients tend to generalize their vulnerability to COVID 19 yet in reality the vulner-



ability is varied and depends on a number of factors such as cancer type, staging and specific therapies, age of the patients and other immunological factors. This generalization by cancer patients leads to unrealistic and unsubstantiated, high perceived vulnerability of cancer patients to COVID 19, with disastrous mental health consequences for the patients. Yet in reality the vulnerability varies from patient to patient which some patients having to even continue with their treatments during COVID 19 epidemic, upon advice from the multidisciplinary team of health experts. Patients with hematological, lung or breast cancer are more vulnerable than those with other cancers [11]. There is, therefore, need for advice and health education to cancer patients, tailor-made for each patient instead on one size fits all messaging.

Currently, no studies are yet available that has investigated the risk of untreated malignancy while waiting for COVID-19 to subside versus the risk of exposure to the virus during cancer treatment. However, in some instances, the postponement of cancer treatment may lead to further progression of cancer especially in patients with aggressive cancers. [16] noted that cancer is a life-threatening disease and treatment should adhere to periods and frequency given in the treatment guidelines. Therefore, any interruption of care can be life threatening and may have detrimental effects on the patients' physical and mental well-being [17]. This study shows interruption of cancer treatment services mostly at public hospitals which at times resulted in postponement of cancer treatment sessions. This confirms a study by [6] which also noted that during the onset of COVID 19 in Zimbabwe, oncology and specialist services at public hospitals were interrupted. Thus, cancer service delivery, during the onset of COVID 19 in Zimbabwe, was not treated with the urgency that it deserves.

Usually, the decision as to whether treatment should be offered or deferred is left to the judgment of multi-professional healthcare teams and particularly oncologists who are responsible for the management of cancer patients [3]. It is however, universally imperative that the reasons for either continuing with treatment or deferring treatment during COVID 19 epidemic should be well communicated to the patients and at times their care givers. This study shows that

some of the treatment sessions for patients were postponed but however, the reasons for the postponement of the treatment sessions were not well understood by the patients apart from the fact that there was physical disruption of operations at treatments institutions due to COVID 19. Respondents for this study, especially those receiving treatment from public institutions, never alluded to any implications of their continuing with treatment to the risk of COVID 19 infection and any relationship between therapies received and risk of COVID 19 infection.

Moreover, unlike the respondent who received treatment at a private hospital who was called on her mobile phone and notified about the treatment postponement, those receiving treatment from public institutions were not even informed about the postponement of their treatment's sessions up until the time that they arrived at the treatment centre for scheduled treatment. The ideal situation is that communication between the health professionals who decide on whether a patient's treatment should be continued or postponed, and the cancer patients should be very clear and done in a manner that the patient understands it and is psychologically empowered to either continue or postpone the treatment sessions as recommended. The best way to equip the patients to be psychologically prepared for either continuing or postponement of any cancer treatment is to show the patient that the decision is in the interest of the patient and its evidence based. Care givers should also be involved depending on the condition of the patient.

The idea here is to empower the patients to participate throughout the treatment process. Zimbabwe's Patient Charter (Ministry of Health and Child Care) is very clear as to the rights of the patients to information pertaining to the decision/advice of the health professional about the patients' health condition and inferably on whether treatment should be deferred or continued. Early studies about communicating with a cancer patient in Zimbabwe [18] underscored the need for open communication between the doctor and the patients in cancer care. Therefore, the failure to inform the patients by the public institutions was likely to be a result of the ill preparedness of the public institutions during the onset of COVID 19 epidemic. Thus, [19] noted that anecdotal reports



show a huge disruption to many health services, including services for antiretroviral treatment delivery, immunization, pregnancy and neonatal care, diabetes, hypertension, and cancer. [5] also highlighted the gaps in COVID 19 response during the onset of the COVID 19 epidemic in Zimbabwe. [6] also noted that during the onset of COVID 19 in Zimbabwe, oncology and specialist services at public hospitals were interrupted. The outpatient departments and elective surgical operations were stopped at the onset of the outbreak including for patients with cancers. Other studies in Zimbabwe highlighted that communities raised significant concerns that a singular focus on prevention and treatment of COVID-19 would lead to the critical needs of those suffering with other diseases being neglected [20]. This is all confirmed by the findings of this study which shows that adjustments at treatment institutions impacted negatively on the cancer patients requiring treatment during the COVID 19 period.

It also emerged from this study that the livelihood of the cancer patients was highly compromised as a result of COVID 19. All respondents faced livelihood challenges during COVID 19 period. The most common challenges include, loss of income, shortage of food, need for monthly rentals and schools' fees for the children. The COVID 19 induced lock down impacted negatively on the income of the respondents. It is clear from the study that the majority of cancer patients depend on self-employment, mostly unregistered vending. The lock down measures impacted negatively on these informal businesses since they were not considered "essential services" in the national COVID 19 regulations, yet the majority of Harare residents rely on informal/unregistered businesses. Some cancer patients could not get basic needs such as food. This situation was similarly faced by cancer patients in other developing countries. Studies carried out in India also showed that financial/income concerns were some of the major concerns among the cancer patients. [13] noted that access to money, grants, and donations through government schemes, trusts, and various donors are the initial steps for any cancer patient to get treatment. As a result of the lockdown, a lot of these documentation processes and financial planning of patients have been placed on hold. Moreover, O'Neil, *ibid*,

highlighted those socio-economic disparities present during, and in the aftermath of pandemics such as COVID 19 and natural disasters appear to enhance the psycho-social impacts of such epidemics on non-communicable diseases.

The study revealed that cancer patients are failing to access the required medication due to both unavailability and high cost associated with cancer medicines in Zimbabwe. Some patients run out of home-based care essentials such as bandages and medication for nursing wounds, colostomy bags for those with stoma (colon cancer patients). High cost of medication also results in postponement of treatment sessions as the patients could not afford the medication. Some patients were supposed to receive treatment on monthly basis as part of palliative care schedules to relieve them from cancer pain and this means that during COVID 19 period they had to endure unbearable pain without any medical intervention. Similar study findings were also noted by [13] in India where patients who were on active treatment and need chemotherapy were unable to access chemotherapy. This has led to a break in their treatment and caused a lot of stress to patients and their oncologists. However, the Zimbabwean situation, noted in this study is different from the Indian situation in that, in Zimbabwe, inaccessibility to medication is not only necessitated by the lockdown measures induced by COVID 19 but also by perennial challenges of high cost of cancer medication which persisted for years before the onset of COVID 19 in Zimbabwe. Thus, COVID 19 worsened the challenges emanating from an already fragile health system. The public health institutions' perceived performance scores by the respondents of this study (Presented in table 2), clearly shows that satisfaction of the cancer patients on services received at public hospitals was better, though not very high, before COVID 19, but then nosedived during COVID 19. Similar qualitative studies in Harare, Zimbabwe, by [21] before the onset COVID 19 in Zimbabwe already shows that Zimbabwe's health system had constraints in cancer care which included: limited access to cancer treatment and care, inadequate health workers, reliance of patients on out-of-pocket funding for treatment services and lack of back-up for major treatment equipment. It is these perennial constraints in Zimbabwe's cancer care



system that has been exacerbated to unprecedented levels by the onset COVID 19.

Medical insurance has been considered crucial in improving accessibility to health services. This study revealed that all the participants were not covered by any form of medical insurance, and they had to finance their medical expenses through out-of-pocket expenditure. This worsened inaccessibility of medication during the COVID 19 period. Cancer patients receiving treatment at public institutions ended up having to go to private pharmacies to purchase cancer related medication due to unavailability of medicines at public facilities, yet private pharmacies charge exorbitant prices in United States (US) dollars and if they accept local currencies their exchange rates were very high compared to the Reserve Bank of Zimbabwe (RBZ) Foreign Exchange Auction official rates.

India studies by [13] shows that transport to the main cities to access treatment was a challenge during the government induced lockdown measures. Similarly, this study shows that cancer patients faced transport challenges as well. Some could not be allowed to pass; others could pass after a long time of interrogation by the security agents, others had to endure waiting in long queues to reach the security checkpoints despite their debilitating health condition. At times, cancer patient care givers accompanying the patients to the treatment centres could not be allowed to pass through, especially if the patient shows no physical signs of sickness, at least to the satisfaction of the security agents manning the roadblocks. More often than not, some cancer patients undergoing cancer treatment, depending on a number of factors, may not show any physical debilitation but due to the higher likelihood of psychological problems (invisible to the security agents) the patients will always require a family care giver to accompany them to the treatment centre for emotional support.

Moreover, the caregiver should meet the health professionals at the treatment centre so that they are advised on how best they can care for the cancer patient to facilitate high treatment success rate. It also emerges from the study that at times cancer patients appear to be fit when going for treatment but when medication is administered the body become weak and

they will definitely need a caregiver. One responded indicated that she could go for treatment with public transport but had to hire a private tax back home because of general body weakness after treatment. Thus, the need for a cancer patient to be accompanied by a caregiver is important.

These challenges were further aggravated by the fact that COVID 19 and the resultant lock down measures paralyzed both formal and informal support systems for cancer patients. Family and community support systems were compromised. Respondents indicated that they could not get the support they used to get from both formal and informal support systems. Zimbabwe has a fragile health system with the majority of people living without health formal support systems such as medical insurance, hence cancer patients heavily depend on informal support systems such churches, family members, community members and well-wishers. The government of Zimbabwe' welfare social system for old age patients (whereby patients aged 65 years and above are exempted from paying at public institutions) was acknowledged in this study. However, in as much as the old age social welfare is helpful as noted in this study, it is not comprehensive since it only covers the consultation and admission fees at the public institutions. Patients still pay for medication. In reality, due to unavailability of cancer drugs at public institutions, these old, aged patients have to buy medication from private pharmacies.

Apart from the well documented double biological vulnerability of the elderly people to COVID 19 infection [22], this study also revealed that the elderly cancer patients face more challenges due to having no viable sources of income to pay for medical bills and also to cushion themselves during the promulgated lockdown measures. Thus, this study revealed the double tragedy of the vulnerable elderly cancer patients during the COVID 19 period in Zimbabwe. Zimbabwe's old, aged welfare only applies to public institutions and only covers consultation fees, hence not comprehensive, thus even old age patients have to pay for their cancer related medication. Similarly, old age discrimination and other challenges related to social security during COVID 19 have been reported in various country across the world including, sub-Saharan African countries



such as Kenya, Rwanda and Tanzania [23].

Most of the respondents in this study were self-employed, mostly as unregistered vendors hence could not get an income during the COVID 19 induced lockdown. The family members who used to assist cancer patients could not fulfil their family responsibility of supporting their relatives with cancer due to the fact that the majority of them were employed in the informal sector hence could not go to work during the lock down since their work is not considered essential services in the COVID 19 regulations. Even formal cancer patient support systems were not spared by COVID 19. The Cancer Association of Zimbabwe's medical support grant was exhausted, and they could not support more patients who needed support despite overwhelming requests from cancer patients.

### Limitations

The study was carried out during the COVID 19 period when both the national guidelines on COVID 19 and the Cancer Association of Zimbabwe's occupational safety guidelines to minimise face to face interactions as part of a COVID 19 control measures. The study therefore employed telephone-based interviews which deprived the researchers of nonverbal communication of the respondents that could have enriched the data collected. The study focused on purposively sampled Harare city cancer patients that had visited the Cancer Association of Zimbabwe clinic during the COVID 19 period. The non-probability sampling and the inclusion criteria limited the scope of this study. Thus, study findings should be interpreted within the scope of these methodological limitations.

### Conclusion

The study revealed that cancer patients faced a number of challenges during the COVID 19 period. The challenges were as a result of COVID 19 itself, resultant lockdown measures and the changes instituted at the cancer treatment institutions. Common challenges faced by cancer patients include mental health related problems, transport related problems, livelihood challenges, medical related difficulties and collapse of both formal and informal cancer support systems. Cancer patients' experiences showed that COVID 19 made it

difficult for them to access cancer treatment and cope with their cancer diagnosis. Both formal and informal cancer support systems were weakened by COVID 19 thereby leaving the cancer patients without any meaningful support during the trying period of COVID 19 in Harare, Zimbabwe. To date (date of publication), no COVID 19 period specific, patient centred efforts have been done to ameliorate the plight of cancer patients in Harare, Zimbabwe. Cancer care should therefore, be prioritized and be integrated with current efforts to control COVID 19 pandemic to avoid suffocation of cancer care service delivery. Innovative patient centred platforms such as mobile based information updates on treatment schedules, review of national COVID 19 guidelines such as enabling operationalization of the "patient's exemption" from travel restrictions and curfew, should be considered. Urgent revival of government patients' support systems such as "assisted medical treatment orders" (AMTOs), social protection and improving home-based care for cancer patients and having a separate cancer fund can go a long way in improving cancer care during the COVID 19 period.

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**Data Availability Statement:** Data is available upon reasonable request from the corresponding author. The request should consist of an official letter and any supporting documents for verification by the Cancer Association of Zimbabwe research team

**Conflict Of Interest:** No potential conflict of interest

**Ethical Approval:** The study adhered to all ethical considerations. It received approval from Cancer Association of Zimbabwe board (authorisation letter available) and is part of Cancer Association of Zimbabwe's national cancer service delivery rapid assessments during COVID pandemic in Zimbabwe.

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