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COVID-19 Pandemic: Psychosocial Distress and Social Burdens Experienced by Cancer Patients at Cancer Diseases Hospital, Lusaka, Zambia

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Abstract

Background: Cancer diagnosis has been reported in some studies to have a significant psychosocial impact on both the patients and their caregivers. The estimated prevalence of psychosocial distress is between 35% and 55%. Commonly encountered psychological issues include and are not limited to fear, anxiety, and emotional distress. Many sources of emotional distress in patients with cancer during the COVID-19 pandemic have been reported to include poorly controlled symptoms arising from a lack of access to symptom control services and treatment. Social distress is associated with social isolation, separation from family and loss of employment. Cancer patients and society have been reported to experience anxiety, despair, and stress due to the COVID-19 restrictions on community movement and hospital appointment rescheduling. The objective of this study was to explore psychosocial distress and social burdens experienced by cancer patients during the COVID-19 pandemic. **Methods:** A descriptive phenomenological design was employed to describe "lived experiences of patients with Cancer" during the COVID-19 Pandemic. A total of 20 participants with Cancer and COVID-19 positive were purposefully selected and interviewed. Thematic analysis was utilized for data analysis by the use of themes generated from participants' responses. **Findings:** Five major themes emerged: fear, self-isolation compliance, anxiety, low income and emotional distress. The findings of the study indicated that participants experienced fear, emotional distress and anxiety when diag-

nosed with COVID-19. **Conclusion:** The experiences of psychosocial distress and social burdens were a result of a lack of psychosocial support by both caregivers and health care workers. This study recommends appropriate health education concerning psychosocial support for cancer patients and the need to have appropriate clinical protocols and materials in allaying anxiety and fear in cancer patients during the COVID-19 pandemic.

Keywords

Cancer Patients, COVID-19 Pandemic, Psychosocial Distress and Social Burdens

1. Introduction

The Corona Virus Disease (COVID-19) outbreak was declared a public health emergency of international concern on January 30, 2020 and a pandemic on 11th of March, 2020 [1]. Globally, there were 33, 603,488 confirmed cases and 1, 007, 438 confirmed deaths as of 29th September 2020 [1] and Zambia recorded 14, 660 cases and 332 deaths. The first case of COVID-19 was on March 18, 2020. The pandemic has posed several challenges to the delivery of cancer treatment, as the patients are unable to visit the cancer treatment facility, procure necessary drugs, or reach the cancer care provider locally for treatment continuation. The pandemic has further worsened inequitably distributed cancer care facilities, preventing a large proportion of patients from accessing medical care when they need it the most [2].

A cancer diagnosis has been reported to have a significant psychosocial impact on both the patients and their caregivers [3]. The estimated prevalence of psychosocial distress is between 35% and 55% [2] [4]. Many sources of emotional distress in patients with cancer during the COVID pandemic have been reported to include poorly controlled symptoms arising from a lack of access to symptom control services and treatment. Social distress is associated with social isolation, stigmatization of illness, separation from family, loss of employment, and poverty [2]. A study conducted by Qui [5] in China during the quarantine in Wuhan showed that up to 35% of people experienced psychological distress). The emotional impact is also evident in another study from China, which showed that 16.5% of the general population had moderate-to-severe depressive symptoms, 8% suffered from stress, a more than 28% had anxiety which was moderate to severe [6].

In Zambia, health care services for cancer patients at the Cancer Diseases Hospital (CDH) were rescheduled during the pandemic for social restrictions. This disruption to scheduled oncology services may lead to emotional distress arising from lack of symptom control, limited access to cancer treatment, curtailment of care, and uncertainty about the course of treatment. In addition to delays in cancer diagnosis and disruption of active treatment plans, cancer pa-

tients may experience distress associated with the risk of contracting COVID-19 infection on a background of immunosuppressive state, social isolation, stigmatization of illness, separation from family, loss of employment, and poverty. Such guidelines are also likely to increase social isolation and loneliness [7], which are independently associated with anxiety, depression, and self-harm [8].

The psychosocial experiences of cancer patients include poorly controlled symptoms arising from a lack of access to symptom control services and treatment. Distress is associated with limited access to cancer treatment, curtailment of care, uncertainty about the course of treatment, disease progression, and premature death. Distress is also associated with accessing cancer services and the risk of contracting COVID-19 infection on an immunosuppressive background state, and social distress is associated with social isolation, stigmatization of illness, separation from family, loss of employment, and poverty [2]. All these factors, if not appropriately mitigated can predispose cancer patients to experience psychological distress and social burdens consequently, predisposing them to depression, anxiety and stress. While social burdens have been studied globally, there is still a paucity of such studies in Zambia.

The current study investigated the COVID-19-related psychosocial distress and social burdens experienced by cancer patients. The study explored social burdens faced by cancer patients which include fear of infection, the success of Covid-19 care, the negative effects of various social isolation prevention procedures, and economic instability that are often correlated with high levels of perceived stress [9]. In Zambia, literature related to the subject of psychosocial and social burdens experienced by cancer patients is still limited despite its importance in providing evidence-based information to health care in addressing the problem.

2. Methodology

This study aimed to determine the psychosocial distress and social burdens experienced by cancer patients during the COVID-19 pandemic. The study was conducted from January 2020 to May 2021. The aim was to explore the phenomena of psychosocial distress and social burdens experienced by patients with cancer during the COVID-19 pandemic rather than speculating their challenges. Therefore, a qualitative descriptive phenomenological design was used, which allowed participants to describe their "lived and real time experiences". The application of this approach enabled researchers to distance themselves from their preconceived ideas regarding patients' experiences and to have more insight into the perceptions of the participants of COVID-19 disease while being affected by cancer. This approach enabled the researchers to comprehend and explain the meaning that participants give to their everyday lives.

Because of the unique set up where these clients are cared for, this study was carried out in Lusaka district (urban) of Lusaka province, at Cancer Disease Hospital. The setting was purposively selected as it reflected and depicted the

specialised healthcare facility in Lusaka.

Eligibility criteria and identification of study participants was purposive sampling, to capture participants. All adult patients, eighteen (18) years and above, living with cancer, suffered from COVID-19 disease and consented to participate in the study participants were invited to participate and share their psychosocial distress and social burdens experienced. However, patients who were critically ill and physically challenged did not participate in the study.

Qualitative research sample size determination relies on the concept of saturation which has become the gold standard by which the samples for qualitative inquiry, like in an interview guide through an in-depth structured interview schedule are employed [10]. A guided interview is a one-on-one directed conversation with an individual that uses a pre-determined, consistent set of questions but allows for follow-up questions and variation in question wording and order. It involves questioning participants either individually or in groups. During the interview, the interviewer gets responses from respondents in a face-to-face encounter, telephone calls or other electronic means. The interview could be structured, unstructured or semi-structured. 20 cancer patients who had suffered from COVID-19 attending healthcare services at Cancer Diseased Hospital were included. Each in-depth interview session lasted for 15 minutes or less.

In-depth Interview Schedules were used to collect data from the patients who involved one-on-one directed conversations with individuals on a pre-determined, consistent set of questions individual participants. This method of data collection was chosen as it helps to get and obtain narrative information about the range of psychosocial distresses and social burdens cancer patients affected with COVID-19 disease experienced. In-depth interview schedule also helped to obtain participants' feedback in clients' own words on specific issues relating to their care, while being diagnosed with COVID-19 disease and seeking health services at Cancer Disease Hospital. The participants brought out specific themes on the range of experiences from uncertainty, anxiety, fear of unknown outcome of their illness and death, self-isolation, low income resulting from loss of employment and interruption of their business during the lock down, panic and irritability evoked as a result of being a cancer patient, affected COVID-19 diseases. The participants further indicated that necessary facts on their care after being diagnosed with Cancer and COVID-19 diseases were lacking. To these effects, three themes emerged from the study as explained by the affected clients, guiding the need to strengthen nursing education, research and practice for improving patient care at this facility.

Data was collected using an in-depth interview guide on 20 participants and transcribed. After collection, data was immediately checked for completeness and accuracy. Analysis was done through thematic analysis which was performed through the process of coding in order to create established meaningful patterns. Two major themes were identified namely the psychosocial distress

and social burdens experienced by cancer patients.

3. Results

All participants interviewed had suffered from COVID-19 pandemic between three to four months ago. Participants discussed their experiences of COVID-19 pandemic and five themes were presented. Socio-demographic characteristics from the study are shown in Table 1.

Table 1 shows that most (55%) of the participants were female while others (45%) were male). On marital status, the majority (65%) of them were married. Participants who attained primary education constituted 9 (45%) and for tertiary education, it was 4 (20%). Those who lived in high density-low income settings were 65% while for low-density middle income there were 7 (35%) participants.

3.1. Psychosocial Distress

Psychological distress in the participants' views entailed the emotional suffering associated with demands from the COVID-19 that were difficult to deal with. This is explained through the three sub themes identified namely fear of uncertainty and death, self-isolation and emotional distress.

3.2. Fear of Uncertainty and Death

"Fear of uncertainty and death" reflected the worries that most people have when faced with a serious illness. COVID-19 being a new condition with a lot of information unknown to most people places a lot of uncertainty on the prognosis

Table 1. Demographic characteristics of sample (n = 20).

VARIABLE		FREQUENCY	PERCENT (%)
Sex of participant	Male	9	45
	Female	11	55
	Total	**20**	**100**
Marital status	Married	12	60
	Single	8	40
	Total	**20**	**100**
Level of Education	Primary	9	45
	Secondary	7	35
	Tertiary	4	20
	Total	**20**	**100**
Type of residential area	High density (low income setting)	13	65
	Low density (Middle income setting)	7	35
	Total	**20**	**100**

and consequently makes people afraid of the outcome. Most of the participants reported having excessive fear of an uncertain future as they did not know whether they would survive the illness or not. They also experienced fear of death arising from high mortality rates that were reported among the people with COVID-19.

Participant 16: "*I didn't even know whether I would get cured from* COVID-19 *illness because of the nature of the illness*".

Participants 5 and 8: "*Many people have died of* COVID-19 *in Zambia*".

Participants 3 and 10: "*The increasing number of* COVID-19 *cases made me worried because it has spread the whole world and people are dying of* COVID-19".

Additionally, literature informs us that people with underlying conditions such as cancer, experience severe outcomes of disease and high mortality due to their lowered immunity. Therefore, most participants reported that having a diagnosis of COVID-19 was like a death sentence to many which led to a number of them developing excessive fear of death. Another concern from the participants was with regards to the suspension of some health services during the lock down period which led to some health services being non-operational; this and many other things worried the cancer patients and increased their fear of death. Anxiety related to the diagnosis of COVID-19 coupled with cancelled review dates further increased the fear of death of most of the participants.

Participant 2 said that "*Sometimes I wondered why I should have two big conditions at the same time and my review for the cancer condition was postponed*".

Participants 6 and 11 said that "*Was thinking about the combination of* COVID-19 *and cancer if I am going to survive because the burden was too much*".

Furthermore, most participants being Christian believed that God heals the sick through a prayer made with faith and this gave a lot of hope to the cancer patients. However, it was noted that the spiritual leaders were not spared from COVID-19 morbidity and mortality and this increased the fear of death in cancer patients with COVID-19. Seeing spiritual leaders, who are expected to pray for the healing of people dying from COVID-19, exacerbated fear and hopelessness in cancer patients.

Participant 12: "*I heard and saw a lot of pastors dying of* COVID-19 *and this made me even more sacred.*"

3.3. Self-Isolation Compliance

"Self-isolation" implied that the cancer patients with COVID-19 were to stay on their own without any friends or family members. This therefore, made the patients afraid to be admitted to the isolation wards because they had no one to take care of them and the nurses were only passing through when it was medication time or during meal times. Most participants expressed sadness at the thought of staying in the isolation ward while there was no one to take care of

the partners and children at home. Additionally, a number of participants stated that during the isolation period the cases of infidelity also increased as the partners who were not in isolation became lonely. This and other reasons made patients not to be interested in admission as some feared for their marriages.

Participant 7 said that "*Imagine as old as am leaving the family home with no one to take care of the children*".

Additionally, participants stated that some patients did not understand the importance of self-isolation as they thought it was a form of treatment yet isolation measures are aimed at stopping the spread of the infection.

Participant 3 *also said* "*What are the benefits of compliance to self-isolation if others have done this but didn't survive*".

Most participants stated that usually sickness in the African context brings people together but this was not the case with COVID-19 as friends and relative were not allowed to visit for fear of contracting the disease. This led to the cancer patients who were sick developing feelings that they did not have social support and also had weakened relationships. Additionally, isolation of patients with COVID-19 reduced social cohesion result from the hospital and social movement restrictions that were imposed to stop transmission. As a result, patient developed depression symptoms such as loneliness, hopelessness, rejection and abandonment.

Participants 3, 15, 17, 19, and 20 said that "*Staying in the hospital for a period of time made me miss the social interactions with family and friends*".

Participant 14 said "*I also begun to think about isolation environment and how I will stay in such an environment*".

3.4. Emotional Distress

"Emotional distress" reflected the anxiety and depression that cancer patients with COVID-19 experienced after a diagnosis. Most participants stated that they experienced some form of panic once a COVID-19 test was positive and was afraid to disclose the status to friends and family. They further reported that hospital environment where patients were admitted was very intimidating as they saw a lot of strange machines and equipment's being used in the wards which further increased their panic.

Participant 14 narrated that "*I felt terrified when I was told I had* COVID-19 *and begun to panic because I heard that some are dying of* COVID-19. *I began to think about isolation environment and how I will stay in such an environment. This made me feel even more terrified and panicked. The health personnel tried to explain but I was not myself*".

Additionally, the members of staff who were attending to the patients wore protective clothing's which covered their entire body and leaving no part exposed. This made the patients realize how serious the condition was and increased the patients' fears as they now realized death was very near.

Participants 4, 10 and 12 said that "*When I saw the attire which the nurses and doctors were putting on, in the isolation ward, I became scared and this in-*

creased panic within me".

Furthermore, some patients reported developing fear in routine activities that came as a result of hospitalization. In turn, these steered anger and irritability.

Participant 13 said that "*I became easily emotional, angry and irritable because of too much worry about* COVID-19".

Participant 16 said that "*Sometimes I could answer back in an irritable way when nurses were asking me how I was feeling but later I asked myself why I was behaving like this*".

Additionally, they also expressed concern about the effects of COVID-19 which were known and others unknown as most of them believed that once a person was diagnosed with COVID-19 they became infertile and were not as sexually active as they were before the condition.

Participant 5 said that "*My friend who had covid shared that he could perform properly in bed after* COVID-19."

3.5. Social Burdens

Social burdens in this context reflected the interaction between the expected normal life led by cancer patients with COVID-19 and the perceptions of the socio-cultural context in which the condition existed. This was explained in the two sub themes identified namely disruption of income generating ventures, and stigmatization.

3.6. Disruption of Income Generating Ventures

Disruption of income generating ventures reflected the changes that took place after a patient was diagnosed with COVID-19. Most participants stated that due to illness and lockdown measures businesses and normal running of businesses were disrupted. This affected productivity both in the formal and informal sectors. The low levels of productivity meant having low output and consequently leading to a number of people being retrenched as companies had not much money to sustain the high numbers of workers. This development also led to an increase in poverty levels among the cancer patients.

Participant 15 stated that "*During lock down, I stopped selling at the market because there were no customers to buy my merchandise*".

Additionally, participants reported that people could not continue with cross border trading due to restriction that was effected to stop COVID-19 transmission among Nations.

Participant 12 said that: "*It was such a bad moment for me because that very time, I was supposed to go on a business trip to Nakonde but could not because I was in the hospital. Even after discharged, I could not go to the market to do business because of the lock down measures*".

3.7. Stigmatization

"Stigmatization" reflected the manner in which the cancer patients with COVID-19

were treated in the community and work places which consequently affected how they generally look at things. Most participants reported that once people in the work place and or communities knew that you had COVID-19, a number of them would start to isolate themselves from you. They would not want to sit in the same place with you or use the same equipment that you used for fear of contracting the disease.

Participants 1 and 15 said that "*After discharged from the hospital, I went back for work and was told that I was terminated from employment because of the long stay in the hospital. My boss said that I can't continue working because I suffered from* COVID-19".

Most participants reported that there is a belief that COVID-19 patients are never completely healed of the disease. They stated that in some cases patients stigmatized themselves while other times the community stigmatized them.

4. Discussion

The study showed that COVID-19 continues to be a major concern globally and that cancer patients are likely to experience psychological and social burdens associated with the condition. The findings also showed that most patients are likely to experience fear, self-isolation, anxiety, low income, emotional distress, and stigmatization.

4.1. Psychological Distress

Psychological distress emerged as a serious concern as most cancer patients had experienced fear of death, self-isolation and emotional distress. Most participants reported having a fear of death and uncertainty about treatment. Similarly, a study by [5] [6] in China showed that participants experienced psychosocial distress, fear and anxiety as a result of the pandemic of COVID-19, disruption of treatment, disease progression and death. This fear experienced by the cancer patients with COVID-19 could be attributed to the uncertainties surrounding the condition and most people do not have adequate information about the condition. Due to fear, most people are also likely not to disclose a diagnosis of COVID-19.

Participants also reported having challenges with self-isolation once a diagnosis was made. During the period of illness, the patients were asked to self-isolate and they had difficulties doing so because of the hospital environment and nature of the disease. These study findings are similar to those from a study done by [7], where participants expressed sentiments regarding isolation and self-protection. Another aspect that led to the increase in isolation was the global recommendation of asking countries that were badly hit to go on lockdown. This was a good preventive measure but it also contributed to the loneliness and also contributing to social isolation. On the contrary, a study by [9] [11] showed that to others self-isolation was not an issue and they expressed familiarity as with physical protective measures when they receive chemotherapy treatment.

Some participants also reported that they experienced some loneliness as a result of social distance and felt they needed a lot of support and social contact or a hug. The results of loneliness were also seen in studies done globally by [12] [13]. The loneliness if not properly managed and controlled could lead to cancer patients with COVID-19 going into depression.

Participants in this study reported that they experienced irritability, panic and anxiety as they were diagnosed with COVID-19 besides the already existing cancer burden. They also stated that hearing news of others dying further increased their fear of dying and contributed to their emotional distress. Similarly, a study by [14] on clinical features of patients infected with 2019 novel corona virus in Wuhan showed that people from China also experienced emotional distress and some even had respiratory distress. From the findings we can deduce that anxiety related to COVID-19 can be reduced by ensuring there is adequate information on COVID-19 including clinical protocols on patient care with COVID-19.

4.2. Social Burden

In relation to psychological distress, the social burden also posed a challenge to most cancer patients with COVID-19. Disruption of income generating activities and stigmatization were two themes identified. Most of the participants reported that they experienced some stigma after surviving covid as most people in the community and even workplaces never wanted to be anywhere near the COVID-19 survivors. These findings are similar to a report finding from Hindus times [15], which stated that COVID-19 survivors are greeted with hostile stares even from their family members and neighbours. The stigma experienced by the covid patients could be attributed to the community fear that COVID-19 patients are still contagious even after they have been healed. This therefore makes the community to stigmatize the patients and sometimes the patients start to stigmatize themselves.

4.3. Study Limitations

The study was based on participants' self-reporting. This made it difficult to objectively verify the answers given. Secondly, there was recall bias. Some participants had suffered from COVID-19 months before the study was conducted; hence difficult for them to recall their experience. The limitations were mitigated by asking probing questions and seeking clarifications. This was however mitigated by probing questions.

5. Conclusion

From this study, it is clear that there are psychosocial distress and social burdens experienced by cancer patients during COVID19. The findings are based on the data collected from 20 participants. This shows that most participants had experienced anxiety, fear, self-Isolation compliance, low income and emotional dis-

tress. It further shows that there was insufficient psychosocial support was given to participants because most of the participants had anxiety, fear, and emotional distress. This study recommends appropriate health education concerning psychosocial support for cancer patients who have been diagnosed with COVID-19.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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