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Cancer Patients' Experience of Long COVID-19 at the Cancer Diseases Hospital, Lusaka, Zambia

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Abstract

Objective: To explore the lived experiences of cancer patients diagnosed with Long COVID-19 at the Cancer Diseases Hospital in Lusaka, Zambia. **Design:** A qualitative descriptive phenomenological study was conducted to capture the subjective experiences of cancer patients affected by Long COVID-19. **Setting:** Cancer Diseases Hospital, Lusaka, Zambia. **Participants:** Fourteen cancer patients with Long COVID-19 were purposively selected using data saturation as the guiding principle. **Methods:** Data were collected through in-depth, face-to-face interviews using Vivo, a mobile data collection tool and analyzed using thematic analysis. Emergent themes reflected key domains of patient experience. **Results:** Four major themes emerged from the data: disruption of cancer treatment, psychological distress, healthcare access challenges, and coping mechanisms. Participants reported significant interruptions in chemotherapy and radiotherapy services due to Long COVID-19, which led to delays in treatment schedules and heightened concerns about disease progression. Psychological distress was common, with many individuals experiencing anxiety, depression, and a pervasive fear that their cancer might worsen. Healthcare access was further compromised by financial constraints, systemic inefficiencies, and limited availability of critical resources. Despite these challenges, participants adopted various coping mechanisms, including reliance on spirituality, support from family and peers, and inner resilience, to navigate the complexities of their dual health conditions. **Conclusion:** Long COVID-19 significantly exacerbated the clinical and psychosocial burden of cancer patients in Zambia, revealing gaps in service continuity and mental health support. An integrated care model addressing both oncologic and pandemic-related challenges is crucial to improving outcomes for this vulnerable population.

Keywords

Long COVID-19, Cancer Patients, Treatment Disruption, Psychological Distress, Healthcare Access, Coping Mechanisms

1. Introduction

Long COVID-19, defined as the persistence of symptoms beyond four weeks following acute SARS-CoV-2 infection, has emerged as a significant public health challenge, particularly for individuals with underlying health conditions such as cancer [1] [2]. Cancer patients are not only at increased risk for severe acute COVID-19 but also for prolonged recovery periods, functional impairments, and psychological distress associated with Long COVID-19 [3] [4]. As the pandemic has evolved, attention has shifted toward understanding the long-term consequences of COVID-19, yet the lived experiences of vulnerable populations, especially in low-resource settings, remain poorly documented.

In Zambia, cancer patients often face structural barriers to timely diagnosis, consistent treatment, and follow-up care, even under normal health system functioning [5] [6]. The advent of COVID-19 disrupted oncology services globally, but these disruptions were particularly pronounced in low- and middle-income countries (LMICs), where health systems were already under strain [7]. Reports from sub-Saharan Africa indicate delays in chemotherapy, surgical backlogs, and limited access to palliative care during the pandemic [8]. However, few studies have qualitatively explored how cancer patients in these settings experience the combined burden of cancer and Long COVID-19.

Understanding these lived experiences is critical to inform integrated, patient-centered care models that account for the unique vulnerabilities of oncology patients recovering from COVID-19. A phenomenological approach is well suited for uncovering how patients make sense of their dual illness experience, as it foregrounds subjective meaning, emotion, and the social context of illness [9]. This study, therefore, aimed to explore the lived experiences of cancer patients diagnosed with Long COVID-19 at the Cancer Diseases Hospital in Lusaka, Zambia.

2. Methods

2.1. Study Design and Setting

A qualitative descriptive phenomenological design was employed to explore the lived experiences of cancer patients with long COVID-19. The study was conducted at the Cancer Diseases Hospital (CDH) in Lusaka, Zambia, the only tertiary cancer care facility in the country, with a bed capacity of 252. CDH functions as a referral centre for oncology patients from across Zambia and neighbouring countries, offering a context rich in clinical and experiential diversity.

2.2. Participants

The study population comprised adult cancer patients receiving treatment at the Cancer Diseases Hospital (CDH) who had a documented diagnosis of long COVID-19. In these patients, long COVID-19 was diagnosed based on the persistence of symptoms or signs for a minimum of three months following a confirmed COVID-19 infection, with no other identifiable cause for the symptoms. Clinicians confirmed each case through a thorough clinical evaluation, including review of medical history, symptom progression, and relevant laboratory tests, to rule out alternative explanations such as cancer progression or treatment-related effects.

Participants were eligible for inclusion if they were medically stable, able to communicate effectively, and provided written informed consent. Individuals who were critically ill or undergoing intensive treatment that could interfere with interview participation were excluded.

The study population comprised adult cancer patients receiving treatment at CDH who had a documented diagnosis of long COVID-19.

2.3. Sampling and Sample Size

Purposive sampling was used to recruit 14 adult cancer patients with long COVID-19 from the 2023 Cancer Diseases Hospital (CDH) database, which recorded 2420 such cases over a three-year period. Participants were identified in collaboration with oncology healthcare staff and included both males and females with various cancer types and stages, although cancer type and stage were not used as selection criteria.

2.4. Data Collection

Data were collected through face-to-face, in-depth semi-structured interviews conducted in a private setting within the hospital. An interview guide was used to direct conversations, focusing on the participants' experiences of living with long COVID-19 while undergoing cancer treatment. All interviews were audio-recorded with the participants' consent, transcribed verbatim, and supplemented with field notes. Identifying information was removed to protect confidentiality.

2.5. Data Management and Analysis

The data were stored electronically in password-protected files, with identifying features coded or anonymised. Thematic analysis was conducted following Caulfield's six-step approach: familiarisation with the data, generation of initial codes, identification of themes, review of themes, definition and naming of themes, and production of the report. This structured framework facilitated an in-depth, systematic interpretation of participant narratives.

2.6. Quality Assurance

Trustworthiness was maintained using Lincoln and Guba's criteria. Credibility was enhanced through member checking and triangulation; dependability through comprehensive documentation of the research process; transferability via thick description of the study context and participant backgrounds; and confirmability through reflexive journaling and independent peer debriefing.

2.7. Ethical Considerations

Ethical approval was obtained from the University of Zambia Biomedical Research Ethics Committee (Reference number: 5021-2024). Permission to conduct the study was granted by the Cancer Diseases Hospital. Written informed consent was obtained from all participants. Confidentiality and anonymity were strictly observed throughout the study.

3. Results

3.1. Participant Demographics

Table 1 summarizes the demographic characteristics of the 14 participants diagnosed with cancer and long COVID-19. Participants' ages ranged from 30 to 65 years, with a mean age of 46.4 years (SD 10.7). Monthly income varied between ZMW 2000 and ZMW 10,000, with a mean of ZMW 5464 (SD 2636). The majority were male (57.1%), and educational attainment ranged from primary to tertiary levels, with over half (57.1%) having completed secondary education. Participants represented diverse occupational backgrounds, including teachers, civil servants, business owners, retirees, farmers, and engineers, reflecting a range of socioeconomic statuses within the sample.

Table 1. Demographic characteristics of participants (n = 14).

Variable	Frequency	Percentage (%)
Age (years)		
Minimum	30	
Maximum	65	
Mean (SD)	46.4 (10.7)	
Gender		
Male	8	57.1
Female	6	42.9
Occupation		
Teacher	2	14.3
Civil Servant	3	21.4
Small Business	2	14.3
Retired Officer	2	14.3
Farmer	1	7.1
Engineer	1	7.1
Trader	1	7.1
Business Owner	1	7.1
Retired Teacher	1	7.1

Continued

Education		
Primary	1	7.1
Secondary	8	57.1
Diploma	3	21.4
Tertiary	2	14.3
Monthly Income (ZMW)		
Minimum	2000	
Maximum	10,000	
Mean (SD)	5464 (2636)	

3.2. Emerging Themes

Four key themes emerged from the data analysis, grounded in the participants’ lived experiences with cancer and long COVID-19: 1) Impact of long COVID-19 on cancer treatment; 2) Psychological distress from long COVID-19 symptoms; 3) Coping mechanisms employed by patients; 4) Healthcare access and support challenges. These themes and their subthemes are summarized in **Table 2**.

Table 2. Themes and subthemes emerging from data analysis.

Theme	Subtheme	Codes
1) Impact of Long COVID-19 on Cancer Treatment	Treatment delays Disrupted progress	Missed appointments, delayed chemotherapy, recovery delays Worsened health, relapse, prolonged treatment
2) Psychological Distress from Long COVID-19	Emotional toll Anxiety and fear	Hopelessness, mental exhaustion, uncertainty Fear of death, isolation, mental breakdown
3) Coping Mechanisms Used by Patients	Social support Spiritual resilience	Family support, virtual connections, peer groups Prayer, humor, journaling, self-care
4) Healthcare Access and Support Challenges	Treatment delays Financial burden	Appointment cancellations, lack of resources, overwhelmed system Medical costs, transport challenges, inadequate insurance

3.2.1. Theme 1: Impact of Long COVID-19 on Cancer Treatment

Participants described how Long COVID-19 significantly disrupted their cancer care trajectory. Two major subthemes emerged: treatment delays and disrupted progress.

Treatment Delays

Participants expressed that Long COVID-19 led to significant postponements in their cancer treatments. Many described feeling as though their cancer journey had been put on hold.

“*My chemotherapy was delayed for almost a month because I had to recover from the Long COVID symptoms first. The doctors said it wasn’t safe to continue while I was still weak.*” (P1, 35 years)

“*It felt like I was fighting two battles at the same time cancer and Long COVID.*

I just wanted to get back to my treatment, but the symptoms wouldn't go away." (P2, 58 years)

"*I thought I was doing well with my cancer treatment, but when Long COVID hit, it was like starting over again. I felt like I had regressed.*" (P10, 52 years)

Disrupted Progress

Long COVID-19 symptoms such as fatigue, respiratory complications, and prolonged weakness disrupted the continuity of cancer care for many participants. This interference not only delayed treatment but also weakened patients physically and emotionally. Several participants reported setbacks in their recovery timelines and described feelings of helplessness and anxiety due to missed appointments and inconsistent follow-ups.

"*I had breathing difficulties from Long COVID, and it made me miss several of my radiation appointments. This slowed down my progress.*" (P4, 60 years)

"*I was very anxious because every time my treatment was delayed, I felt like my cancer was getting worse. It was a scary feeling.*" (Anonymous)

"*I was advised to prioritize recovering from Long COVID first, but in the back of my mind, I was thinking about how far behind my cancer treatment was getting.*" (P14, 41 years)

"*Being in the hospital for cancer was already stressful, and Long COVID just added another layer of difficulty. I couldn't see my doctors as often, and that scared me.*" (P6, 50 years)

3.2.2. Theme 2: Psychological Distress from Long COVID-19 Symptoms

Participants described significant psychological distress stemming from their experience of Long COVID-19 while undergoing cancer treatment. Two subthemes emerged: emotional toll, and anxiety and fear.

Emotional Toll

Many patients reported feelings of exhaustion, loss of control, and a deep sense of isolation. Persistent symptoms like brain fog and fatigue made it harder to engage with their daily routines or stay hopeful about recovery. Social disconnection and mental exhaustion further compounded their distress.

"*The fatigue and the brain fog made me feel like I was losing control over my life. I was scared that I wouldn't recover from either illness.*" (P11, 65 years)

"*I was cut off from my family and church gatherings for some time, which made me feel very alone. It wasn't just the physical pain, but the emotional toll was unbearable.*" (P8, 33 years)

"*I was already dealing with the stress of cancer, and then when the Long COVID symptoms wouldn't go away, it felt like everything was falling apart. I couldn't sleep, and I was constantly worried.*" (P3, 42 years)

Anxiety and Fear

Participants described overwhelming anxiety and persistent fear about their health and future. The dual diagnosis made it difficult to remain optimistic, and some reported a loss of hope and increased depressive symptoms.

"*Dealing with cancer is already overwhelming, but with Long COVID, it was* *like a never-ending cycle of fear and uncertainty. Some days I didn't even want to get out of bed.*" (P6, 50 years)

"*I used to be optimistic about beating cancer, but Long COVID made me lose that hope. I became more depressed and anxious about my future.*" (P10, 52 years)

"*I couldn't tell what was worse anymore, cancer or Long COVID. I was constantly terrified of what would happen next, and that fear stayed with me.*" (P13, 36 years)

"*It's exhausting—physically, yes, but mentally even more. I wasn't just fighting the symptoms; I was fighting the fear and worry that came with them.*" (P9, 44 years)

3.3.3. Theme 3: Coping Mechanisms Used by Patients

Despite the hardships, participants employed various coping strategies to manage the dual burden of cancer and Long COVID-19. Two subthemes were prominent: social support and spiritual resilience.

Social Support

Social support, both physical and virtual, played a critical role in helping patients manage emotional stress and maintain hope. Family encouragement, peer interactions, and support groups provided a sense of community and strength.

"*I joined an online support group for cancer patients. Hearing other people's stories and struggles made me feel less alone in this fight.*" (P5, 49 years)

"*Having my family around me, even virtually, made a big difference. They were my source of strength, and their encouragement kept me going.*" (P9, 44 years)

"*I celebrated small milestones, like days when I could breathe a little better or when I had more energy. It gave me hope that things would get better.*" (P3, 42 years)

"*I started journaling to keep track of my symptoms and progress. Writing things down helped me see improvements, even if they were small.*" (P14, 41 years)

"*I had to constantly remind myself that I was fighting for my life. Keeping a positive attitude helped me push through the difficult days.*" (P7, 30 years)

Spiritual Resilience

Faith and spirituality served as vital sources of hope and emotional strength. Patients also adopted self-care routines and even humor as coping tools. Mental resilience was strengthened by focusing on acceptance and believing in personal strength.

"*I turned to prayer during this time. It gave me strength when I felt like giving up. My faith helped me believe that I could recover.*" (P12, 47 years)

"*I made sure to eat well, rest, and do breathing exercises. Taking care of my body was one way I could feel like I had some control.*" (P6, 50 years)

"*I tried to find humor in small things. Laughing helped me forget the pain for a while, and it was a way to lift my spirits.*" (P8, 33 years)

"*It wasn't easy, but I kept telling myself that I was stronger than the illness. Believing in my own resilience was key to getting through this.*" (P1, 35 years)

"*I learned to accept that some things were beyond my control. Once I stopped fighting the things I couldn't change, I found more peace.*" (P10, 52 years)

3.3.4. Theme 4: Healthcare Access and Support Challenges

Participants reported systemic barriers to accessing healthcare. The pandemic disrupted care pathways, strained hospital resources, and added financial burdens to an already complex medical condition. Two subthemes emerged: treatment delays and financial burden.

Treatment Delays

Many participants encountered postponed appointments, insufficient attention, and poor coordination between oncology and COVID-19 care teams. These barriers left participants feeling neglected, frustrated, and uncertain about their treatment outlook.

"*Because of the COVID restrictions, I couldn't get the care I needed right away. Appointments were pushed back, and I was left waiting for weeks.*" (P2, 58 years)

"*There were times when I felt like the doctors didn't fully understand how to manage both my cancer and COVID symptoms. I needed more specialized care.*" (P11, 65 years)

Financial Burden

The cost of managing two complex conditions simultaneously was overwhelming for many participants. Long COVID added a financial strain on top of existing cancer-related expenses. Several mentioned issues with transportation, medication affordability, and lack of insurance support.

"*The costs just kept piling up. Not only was I paying for cancer treatments, but I also had to deal with the costs of managing Long COVID. It was overwhelming.*" (P10, 52 years)

4. Discussion

This study explored the lived experiences of cancer patients with Long COVID-19 in a resource-limited context, revealing deep disruptions to care and multifaceted impacts on physical, emotional, and psychosocial well-being. The findings are consistent with existing literature that shows how the intersection of chronic illness and post-COVID conditions intensifies patient vulnerability [10]-[12].

Disruption of cancer treatment was a dominant theme. Participants reported delays in chemotherapy and missed surgical appointments due to lockdowns, transport restrictions, and fear of contracting the virus. This aligns with studies indicating that treatment interruptions were common during the pandemic, particularly in low-resource settings [13] [14]. Prolonged treatment gaps may compromise cancer prognosis and contribute to increased patient anxiety and uncertainty [15].

Psychological distress was also prominent, including feelings of isolation, hopelessness, and fear. Such emotional experiences are documented in literature examining cancer patients during the pandemic, where the lack of physical support networks and limited contact with healthcare providers exacerbated mental health struggles [16] [17]. Participants in this study emphasized a sense of abandonment, further worsened by the stigma surrounding COVID-19. This echoes findings in other sub-Saharan African contexts where stigma contributes to poor mental health outcomes and reduced health-seeking behavior [18].

Despite these challenges, participants demonstrated resilience through coping strategies, primarily spiritual practices and faith-based support. This is consistent with prior research indicating that spirituality plays a central role in managing chronic illness and trauma in African contexts [19] [20]. Patients often drew strength from prayer, church communities, and the belief in divine healing, which helped mitigate despair.

Barriers to healthcare access were also highlighted, including distance from facilities, lack of transport, and poor communication with providers. These systemic issues have been magnified by the pandemic but are longstanding in many LMICs [21]. The need for decentralization of cancer services and integration of Long COVID-19 management into routine oncology care emerged as critical areas for improvement. Other studies have similarly advocated for adaptable service delivery models that ensure continuity of care during public health emergencies [22].

Importantly, participants advocated for better communication, follow-up, and psychosocial support. This aligns with global calls for a more holistic, patient-centered model of cancer care that considers the long-term sequelae of COVID-19 and promotes health system resilience [23] [24].

5. Strengths and Limitations

A major strength of this study lies in its phenomenological design, which enabled the collection of rich, in-depth narratives capturing the lived experiences of cancer patients affected by Long COVID-19. The inclusion of participants with varied cancer diagnoses, age ranges, and socio-economic backgrounds enhanced the breadth of perspectives and supported the transferability of findings to similar oncology contexts within the region.

However, the study has some limitations. Conducting the research at a single tertiary referral hospital in Lusaka may limit the generalizability of the findings to more rural or decentralized healthcare settings. To mitigate this, the study purposively included participants from diverse residential areas and socio-economic strata to reflect a range of experiences. Additionally, as Long COVID-19 is a relatively new and evolving condition, there was a possibility of misattribution or underreporting of symptoms. To address this, interviews were guided by an open-ended and exploratory approach, allowing participants to express a wide array of symptoms and experiences without being restricted by predefined categories. Another limitation was the exclusive use of English during interviews, which may have excluded non-English speakers and limited the cultural depth of some responses. To reduce this impact, participants were encouraged to express themselves freely, and clarifications were sought to ensure accurate understanding; however, future research should consider using local languages to enhance inclusivity and cultural nuance.

6. Implications for Practice and Policy

The study highlights the urgent need for integrated care pathways for oncology patients who develop Long COVID-19. In particular, there is a need for routine screening for persistent post-COVID-19 symptoms during follow-up visits and the creation of dedicated referral protocols between infectious disease and oncology departments.

Policy-makers should prioritize investment in health system resilience, including staff training, mental health integration, and access to essential medications. The pandemic has revealed critical vulnerabilities in Zambia's oncology care infrastructure, many of which predated COVID-19 but have now been amplified.

Mental health services must be expanded within oncology settings. Most participants reported experiencing emotional distress without structured psychosocial support. Providing psychological counselling, peer-support programs, and family-based interventions can improve both mental health outcomes and treatment adherence.

Finally, the healthcare system must address economic barriers faced by patients with dual burdens of cancer and Long COVID-19. Financial assistance programs, transport support, and flexible appointment scheduling could reduce treatment interruptions and enhance continuity of care.

7. Future Research

Future research should examine the long-term clinical outcomes of cancer patients with Long COVID-19 in sub-Saharan Africa, particularly in relation to disease progression, treatment response, and survival. Quantitative studies assessing the prevalence and severity of Long COVID-19 symptoms in cancer populations will provide a clearer epidemiological picture. Furthermore, research should explore the experiences of healthcare providers delivering care to this patient group, as well as caregivers' perspectives, to inform more holistic, patient- and family-centered interventions. Longitudinal qualitative studies would also be valuable in capturing how coping mechanisms and support needs evolve over time.

8. Reflexivity and Contextual Considerations

This study was conducted at Zambia's national cancer referral hospital, and while the sample was diverse in diagnosis and background, the findings may not reflect experiences of patients in rural or primary-level facilities. Moreover, as researchers working within the Zambian health system, we recognize that our proximity to the context may have shaped both the framing of interview questions and interpretation of findings. Nonetheless, the consistency of themes across participants suggests that these experiences are shared and significant.

9. Meaning of the Study

This study highlights the complex intersection between Long COVID-19 and cancer in a resource-limited setting. It reveals how already-fragile health journeys are further complicated by systemic disruptions, emotional turmoil, and socio-economic barriers. These insights call for a reimagining of cancer care that is resilient, integrated, and responsive to patient realities beyond the biomedical model.

10. Conclusions

This study provides an in-depth account of the complex, layered challenges faced by cancer patients living with Long COVID-19 in a low-resource setting. Participants reported significant disruptions in care, emotional distress, reliance on spiritual coping mechanisms, and difficulties accessing essential services. These experiences reveal systemic gaps in the continuity and responsiveness of cancer care during health crises.

Health systems in sub-Saharan Africa and Zambia, in particular, must develop more resilient oncology pathways that account for future pandemics and chronic comorbidities like Long COVID-19. The integration of post-COVID care into cancer services, psychosocial support mechanisms, and decentralized service models may help to mitigate the burden faced by these patients. Ultimately, centering patient voices and lived experiences in policy and service design is essential to delivering compassionate, equitable cancer care.

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Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this manuscript.

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