


# Lived Experiences of Adult Cancer Patients Undergoing Chemotherapy Treatment at University of Gondar Specialized Hospital, North West Ethiopia, 2021

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## Abstract

Cancer is a global public health problem and it exposes patients with a wide range of physical, psychological, social, and financial problems. Experiences, feelings and thoughts patients have during the course of the disease are the determining factors of disease management. However, most of the studies analyzing cancer patients' experiences have been performed only in high-income countries and the situation for cancer patients in Ethiopia is largely unknown. This study aimed to explore the lived experiences of adult cancer patients undergoing Chemotherapy treatment at University of Gondar specialized Hospital, Ethiopia. A phenomenological study design was conducted among adult cancer patients undergoing chemotherapy treatment at University of Gondar specialized Hospital. In-depth interview was conducted with 13 participants by using purposive sampling technique from March 15 to April 15, 2021. The data collection process facilitated by using semi-structured Amharic interview guide. After transcription and translation, data were analyzed by using a thematic analysis method. The ATLAS.ti software version 9 was used for coding and categorization. The result was reported using narrative and mentioned indirect quotation. The findings of the study revealed four main themes: "psychological discomfort," "functional status impairment," "experiences about chemotherapy treatment," and "coping mechanism." The findings revealed that being diagnosed with cancer is the most traumatic experience and affect all aspect of a patient life. Despite the side effects, the treatment gives hope for a new life. Social and spiritual supports have importance in coping the negative effects of living with cancer. Therefore, health care providers should provide psychosocial care to cancer patients from there diagnosis and in there treatment in dealing with this difficult process.

## Keywords

cancer, chemotherapy, experiences, adult cancer patient, Ethiopia

## Introduction

Cancer is the leading diseases in the world and its incidences are increasing every year.<sup>1</sup> Globally, 19.3 million cancer cases and 10.0 million deaths occurred in 2020.<sup>2</sup> In Ethiopia, cancer belongs to the second most common non-communicable diseases (NCD) next to cardio vascular disorders.<sup>3</sup>

In Ethiopia cancer is thought to be incurable diseases caused by magic, bad luck, or a divine punishment.<sup>4</sup> Attitudes toward cancer and its treatment options are highly dependent due to the effects of one's belief, values, past experiences, and cultural background.<sup>4</sup> Cancer patients who had negative illness attitude had poor quality of life (QoL) and experienced more stress, anxiety, and depression.<sup>5</sup>

Chemotherapy is a systemic drug therapy used to destroy rapidly growing cells in the body.<sup>6</sup> It is one of the most

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commonly used cancer treatment modalities.<sup>7</sup> Despite its high efficacy, patients may experience multi-dimensional problems, including physical side effects,<sup>6,7</sup> psychological distress,<sup>7</sup> and social problems.<sup>7</sup> All of these can make it difficult for patients to cope with chemotherapy treatment and affect their QoL.<sup>8</sup>

Experiences, feelings, and thoughts patients have during the course of the diseases are the determining factors of disease management.<sup>9</sup> Perception varies from one person to another due to the effects of one's beliefs, values, culture, and past experiences.<sup>10</sup>

Therefore, understanding the lived experiences of cancer patients undergoing chemotherapy treatment is necessary to provide appropriate care and support to the patients. However, most of the studies analyzing the experiences of cancer patients have been performed only in high income countries and the situation for patients in Ethiopia are largely unknown.<sup>9</sup> Discovering these experiences can greatly help to build realistic care programs based on real-world concepts that meet their needs.<sup>11</sup> Therefore, this study aimed to explore the lived experiences of adult cancer patients undergoing chemotherapy treatment at the University of Gondar Specialized Hospital, Gondar, Ethiopia.

## Methods and Materials

### Study Setting and Design

A phenomenological study was used to explore the lived experiences of adult cancer patients undergoing chemotherapy treatment at the University of Gondar specialized hospital (UoGSH). From March 15 to April 15, 2021, the hospital is located in Gondar city 748 km Northwest of Addis Ababa (Capital city of Ethiopia). The oncology treatment center of UoGSH currently has a total of 18 beds for the inpatient management of cancer patients.

### The Study Participants

Cancer patients who are  $\geq 18$  years old, and taking at least three cycles of chemotherapy treatment during the time of data collection at UoGSH were included. The exclusion criteria for the study were participants with mental illness and an inability to communicate.

### Sample Size and Sampling Technique

A heterogeneous purposeful sampling technique was employed to ensure that patients of both sexes and a variety of cancer types were included. The data was collected by an oncology nurse who has experiences on qualitative data collection. The interviews continued until data saturation. In this study, data saturation was achieved at the 11<sup>th</sup> interview; however to ensure that there was no new information, two

interviews were added giving a total of 13 interviews. The duration of the interviews was between 30 and 40 minutes.

### Data Collection and Analysis

Data was collected through individual face to face interviews using a semi-structured interview guide. All interviews were arranged according to the participant's convenience and were conducted in a quiet room at the oncology head offices of UoGSH. An interview guide was developed covering experiences related to cancer diagnosis, chemotherapy treatment, and coping with its negative effects. Probing and follow-up questions were used during the interviews. Before the start of the study, the interview guide was tested on 5 (38.4%) cancer patients undergoing chemotherapy treatment at the University of Gondar specialized hospital before the actual date of data collection. Depending on the result of the test, corrections and modifications were made to the questionnaire before being applied to the study population.

Each individual was briefed about the study, then after obtaining an informed consent the interview was conducted to collect the required information purposefully until information saturation was reached. Interviews were transcribed in to Amharic and then translated in to English. The transcribed text was read and reread repeatedly to gain an overview; words and sentences having similar meanings were identified and coded. Codes with similar meanings were classified into subthemes, which were further grouped into themes that reflected the central content. Data were analyzed using Atlas.ti version 9 software. During the analysis process, the codes, and themes were discussed until an agreement was reached between the authors. The result was reported using narrative and mentioned in direct quotation.

### Data Quality Control

The trustworthiness of the study was assessed through credibility, dependability, conformability, and transferability. To increase the credibility of the data, researchers tried to enroll participants that had the maximum variation in terms of age, occupation, gender, education, education, and type of cancer. Also the initial codes were presented to three participants, and their comments about the suggested codes and compatibility with their real experiences and feelings were evaluated. To evaluate the dependability of the data the codes and extracted categories from the text, the interviews, were presented to one professor with a high number of publications in the field of qualitative research to audit the process of data extraction and categorization. To ensure conformability of data, when the interview is conducted field notes were taken furthermore the interviews were tape-recorded hence the raw data is available. By refining the data collection instrument in the course, by using codes and categorization and by developing themes from the coded data, the data were tried to analyze without personal bias. Transferability

was evaluated by reviewing the results and comparing the findings of the study with the results of similar studies, situations, and common sense.

## Results

A total of 13 patients undergoing chemotherapy treatment have participated in the in-depth interview. The age of patients were ranged from 25 to 60 years with the mean [SD] age of 43.77 [10.85] years. Of them 61.5% were females, and 46.1% were married. The majority 10 (76.9%) of the patients were at stage III and colorectal cancer was the most common case 5 (38.5%) (Table 1). **Experiences of Cancer Patients Undertaking Chemotherapy Treatment**

Experiences related to cancer diagnosis, experiences related to chemotherapy treatment, and experiences related to coping mechanisms were explored from the narration of cancer patients, and four categories of themes emerged, which are psychological discomfort with a subtheme of negative emotion and depressive symptoms, experiences related to chemotherapy treatment with a subtheme of positive and negative experiences, functional impairment with a subtheme of failure in working life and failure in the family role, and coping with the diseases with subthemes of social support and spiritual support.

### Psychological Discomfort

**Negative emotion.** Each cancer patient experienced a wide range of psychological and emotional challenge as a result of cancer diagnosis and its treatment. They reported that negative feelings were the most common psychological problem of cancer patients. It brought a deluge of complex emotions; that is, uncertainty, fear, anxiety, and depression that proved as hard to bear as the diseases itself.

A 33-Year-old female participant says: “When I was diagnosed with cancer, I worried that I would die leaving my little children, and I frequently questioned God why would punish me with this disease” (Code 05).

A 47-year-old female participant says: “I was worried that I would die as a result of these diseases. Sometimes I wish if my disease is HIV/AIDS. Because I see patients with HIV/AIDS who are taking the treatment looks well” (Code 10).

A 44-year-old male participant “I had a family member who died because of cancer so I fear the disease immensely as said in Amharic proverb ‘yeferut yidersal’ (the one you fear will come) I diagnosed with cancer, as that time I couldn’t control myself I was too emotional and fearful, my mind is full of bad things.....However, the physician and nurses make every effort to reassure me” (Code 08).

**Depressive symptoms.** The results showed that some patients became emotionally unstable and started to suffer from loss of independence and autonomy, and this in turn increased their levels of depression.

A 27-year-old female participant says: “It’s the first thing that I am thinking all about the day and night, and I did not like to speak about my disease with anybody....My mood shifted from always being happy to being sad and I lost interest in everything” (Code 04).

A 25-year-old male participant says: “I feel depressed and isolated from my friends and classmates because of the stigma related to the disease” (Code 13).

**Functional status impairment.** Functional status consists of the individual performing normal daily activities, performing the daily roles and maintaining his/her health and well-being. After a cancer diagnosis, there is a physical capacity limitation, which prevents the individual from fulfilling daily responsibilities and causes emotional problems. In this study, patients reported that they have some levels of functional impairment in their roles and responsibilities at work and home that have a negative impact on their life.

**Table 1.** Sociodemographic and clinical characteristics of adult cancer patients undergoing chemotherapy treatment at UoGSH, 2021 (n=13).

Code	Age	Sex	Marital status	Type of cancer	Stage	Occupation
01	48	Male	Married	Colorectal	III	Govt. employee
02	35	Male	Single	Esophageal	III	Farmer
03	45	Female	Divorced	NHL*	II	Self-Employee
04	27	Female	Married	Breast	III	House wife
05	33	Female	Married	Breast	III	House wife
06	50	Female	Married	Colorectal	IV	House wife
07	54	Female	Widowed	Cervical	III	House wife
08	44	Male	Married	Colorectal	III	Govt. employee
09	60	Female	Widowed	Breast	IV	House wife
10	47	Female	Married	Cervical	III	House wife
11	56	Male	Married	Colorectal	III	Farmer
12	45	Female	Divorced	Ovarian	III	Self-employee
13	25	Male	Single	Colorectal	III	Student

\*Non-Hodgkin Lymphoma

**Failure in working life.** A 48-year-old male participant says: “I lost my previous work position and now doing in a lower position because of absenteeism related to my current health condition” (Code 01).

Another 56-year-old male participant says: “I am a farmer because of my disease condition. I couldn’t do my job at all and get earning to live through renting my farm land” (Code 07).

Another 42-year-old female participant says: “I am not doing any work even at home because of fatigue” (Code 07).

**Failure in the family role.** They also reported that there has been impairment in fulfilling their roles and responsibilities. Difficulties in playing the role of the mother, such as caring for children, and being able to do household work was reported by the participants.

A 33-year-old female participant says: “With fatigue due to therapy, I couldn’t play my role as a mother in my home; my little daughter takes care of all the household activities” (Code 05).

A 47-year-old female participant also bothers about her limitation in fulfilling her role at home, she says “....Because of the disease condition, I can’t take care of my children as usual” (Code 10).

A 50-year-old female participant says: “I am fully dependent on my daughter for all the household activities” (Code 06).

### Experiences with Chemotherapy Treatment

**Positive experiences.** Ten from the thirteen participants stated that after they heard about their cancer diagnosis, they were filled with the fear of death; however, chemotherapy treatment despite having a bothering effect, gives hope to live, and have a good progress in their health condition.

A 44-year-old male participant says “After six cycles of chemotherapy treatment, I was in a good spirit, thanks to chemotherapy” (Code 08).

A 35-year-old male participant “Now, I can say I am healthy and in a good spirit, thanks to chemotherapy” (Code 02).

A 54-year-old female participant says: “After I begin chemotherapy treatment, my vaginal bleeding was stopped and now thanks to God I have good progress” (Code 07).

A 56-year-old male participant says: “After starting my chemotherapy treatment, I gradually see an improvement in my health, giving me a second chance to live with my family and beloved” (Code 11).

**Negative experiences.** In this study, all of the participants experienced some level of chemo-related side effects, such as poor appetite, nausea, vomiting, and hair loss. These chemotherapy induced symptoms affect the patient’s daily living and quality of life.

A 27-year-old female participant says: “I am experiencing symptoms such as nausea, vomiting, loss of appetite, and hair loss. I’m concerned about my hair loss, but the doctor’s assured me that it will regrow after I finish the treatment” (Code 04).

A 35-year-old male participant says: “I have no appetite at all, which prevents me from eating solid foods like injera, I even take juices (Atmit) very slowly; because of this I lose weight as you look me” (Code 02).

A 50-year-old female participant says: “I have a poor appetite and trouble falling asleep” (Code 06).

Two participants stated that despite experiencing chemo-related side effects. It doesn’t bother them because they get enough education on the side effect of chemotherapy, and they focus on the outcome of the treatment than the side effects.

A 45-year-old female participant says: “I have a poor appetite, altered taste, nausea, and vomiting, but this doesn’t bother me much because I am aware of the side effects of chemotherapy, and focused on the outcome of the treatment” (Code 03).

A 54-year-old female participant says: “I have nausea, and hair loss, but it doesn’t bother me because my focus is to be healthy and free from disease” (Code 07).

**Coping with the disease.** Almost all of the participants stated in coping with the negative effects of cancer, social support, and spiritual support have a great importance in reducing their worries, and increasing their hope for life

**Social support.** Most of the participants in our study reported that they received good social support from their family members, particularly their spouse, children, and parents during cancer diagnosis and throughout their treatment; which was the most stressful time for them.

The support of family and close friends was very important for the patients to reduce the negative psychological impact of cancer diagnosis and treatment; it improves psychological adaptation, and consequently helping the recovery process.

The participant indicated that support was a critical ingredient to their physical and mental health when they faced cancer. The majority of participants stated that the support they received from their family gives them strength, courage, and motivation to successfully manage the different challenges during the treatment.

A 54-year-old female participant says: “My entire families are very supportive, and I am alive because of their support” (Code 07).

A 27-year-old female participant says: “My husband is a wise and learned man who strongly supports me. He just treated me well, when I say I’m going to stop the treatment, he assures me to continue my treatment and says to me if you stopped the treatment I will not live with you” (Code 04).

A 48-year-old male participant says: “....Yes, all of my family members support me well. I don’t have enough

words to express my gratitude for the care, and love I got from them. They were always by my side when I needed them” (Code 08).

A 38-year-old male participant says: “I have not worried more, because my friends genuinely support me in all spheres, now I can say I am healthy” (Code 02).

Other participant reported a non-supporting spouse, but the other members of the family member and his personal strength helps him to cope with the disease.

A 44-year-old male participant says: “My wife has no awareness about cancer because of that she feels that I will transmit to her and whenever she smells a bad odor, she always says to me you are contaminating me with this disease.... Anyway, my two daughters support me well” (Code 01).

Another participant says that she lives alone, and doesn’t have a family member that support and care, because of this she worried about her future.

A 60-year-old female participant says: “My immediate family has died and currently, I am living alone.... I pray to almighty God not to prolong this disease on me or to take my life early because I don’t have families and don’t want to bother other people” (Code 09).

**Spiritual support.** For all of the participants, religion provided moral and emotional support throughout the process of living with cancer. Spirituality played an important role to decrease anxiety, and depression in cancer patients.

A 42-year-old female participant says: “I have a good relationship with God, and I pray to him to restore my health so that I can go to church and praise him” (Code 10).

A 45-year-old female participant says: “When I diagnosed with cancer, I am not disturbed more because in Islam believing in predestination is part of my faith. So I said let it come as it may, and let it return as it may” (Code 13).

A 40-year-old female participant says: “.... I just pray and talk with Almighty God every day; I ask him to restore my health” (Code 09).

## Discussion

Being diagnosed with cancer is a traumatic experience for patients. Psychological distress is a strong factor behind the battle with cancer and patients reported negative emotions, fear, anxiety, and depression that affect their quality of life. These study findings were consistent with studies conducted in Ghana, Jordan, and Lebanon.<sup>12–14</sup> This could be because of uncertainty surrounding disease prognosis,<sup>15</sup> fear of death,<sup>15</sup> and the oncology treatment in Ethiopia yet not incorporated with psychotherapy or counseling services so the patient’s psychosocial well-being is largely undermined.<sup>16</sup>

In this study, cancer patients who are taking chemotherapy treatment encounter different symptoms, that is, fatigue, nausea, vomiting, and hair loss that affect their daily life activity. This finding was consistent with a study in Rwanda, and Malaysia that reported cancer patients undergoing chemotherapy treatment suffered from a variety of

symptoms such as nausea, vomiting, fatigue, pain and hair loss during their treatment. It has an impact on the patient’s daily living and quality of life.<sup>17,18</sup>

A high number of chemotherapy related side effects in this study could be explained by poor symptom management,<sup>19,20</sup> an underdeveloped healthcare system in Ethiopia in comparison with developed countries.<sup>21</sup>

Chemotherapy treatment despite its side effect creates a new balance toward future goals and achievement of a healthy life. This study showed that, the overall chemotherapy treatment helped in improving their health condition, and giving them hope for a new life. This finding was consistent with studies conducted in Iran, and China that indicated that patients who complete chemotherapy treatment had an improved health status than patients who have not initiated chemotherapy.<sup>22,23</sup> Moreover, a study conducted in the US states that patients with cancer experienced a decrease in the physical, psychological, and social functioning, which have improved after getting chemotherapy treatment.<sup>24</sup>

In this study, most cancer patients undergoing chemotherapy treatment experienced functional impairment in fulfilling their role and responsibility at work and home, such as child care and household activity was affected, this caused anxiety, depression, economic burden, and compromised the QoL of the patients. The finding was consistent with studies done in Syria and the USA.<sup>25,26</sup> The impairment in the family, and work life could be due to advanced cancer stage, anxiety, depression, and distressing symptoms that affect the physical functional status of patients.<sup>27</sup>

Receiving chemotherapy treatment was perceived as difficult, and the experienced side effects negatively influence the physical, social, and psychological dimensions of the patient’s life. Social and spiritual support helped to cope with the negative effects of cancer and its treatment. Social support plays an important role in cancer patient’s sharing the challenges they experience, holding on with their lives and being hopeful for the future.<sup>28</sup> Most of the patients in the present study stated that they received support from their families and friends. They frequently emphasized that social support they received was the main source of fighting the disease, coping with the disease, and being hopeful. This finding is consistent with other studies in Ethiopia, Malaysia and Turkey.<sup>8,28,29</sup> This could be social support helps to buffer the impact of stressors, and improves psychological adaptation, and consequently helps the recovery process<sup>8,25,27</sup> and patients that don’t receive adequate social support are less able to buffer the impact of health stressors, and consequently, their level of despair and loneliness increase and they are at greater risk adverse health effects that affects their QoL.<sup>30</sup>

Spirituality such as prayers has a positive role in coping the negative feeling and improving their QoL. In this study, all cancer patients avail spiritual help as their crucial coping mechanism. This finding is similar to studies done in Pakistan, India, and South Africa.<sup>7,31,32</sup> The participant’s experienced intense spiritual activities, and prayers, and

turning to God through repenting so that the Almighty forgive and restore their health. As a result, spiritual well-being is enhanced their welfare, hope levels and quality of life. In the present study, Ethiopian beliefs, and culture regarding illness influenced the patient's perceptions of cancer treatment. A strong faith in God and believing in destiny resulted in accepting the reality, and provided hope to recover. This could be spirituality give an inner strength in adapting to stress, and is considered as a hope for the future; hence, it improves QoL.<sup>25,32</sup> The first limitation of this study can be; the study explored a brief window in to the total experiences of cancer patients, and the second one can be; although we translated participants quotes from Amharic to English language, the accurate meaning might not have been achieved.

## Conclusion

The findings revealed that being diagnosed with cancer is the most traumatic experience and affect the physical, emotional, and social aspects of their life. Despite the side effects it has, chemotherapy treatment gives hope for a new life that strengthens their emotional spirit. Coping discomforts in the hope of a cure aided the participants in managing the undesired side effects of cancer and its treatment. Social and spiritual supports have an importance in coping the negative effects of cancer and its treatment. Therefore, healthcare providers should provide psychosocial care to cancer patients from the moment they are diagnosed with cancer and during the course of cancer treatment in dealing with this difficult process.

## Abbreviations

NCD	non-communicable diseases
QoL	quality of life
UoGSH	University of Gondar specialized hospital
WHO	World Health Organization.

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## Authors' Contributions

A.N. and A.Z. conceived and designed the study, A.N., A.H. S.K. and H.B. analyzed and interpreted the data. A.K and A.Z. wrote the first draft of the manuscript. All authors reviewed the final version of the manuscript, and agreed to be accountable for all aspects of the work.

## Consent for Publication

Not applicable.

## Data Availability Statement

The data of this study can't be shared publicly due to presence of sensitive (confidential) participants' information.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Ethics Approval and Informed Consent

Ethical clearance was obtained from the institutional review board of Bahir Dar University, College of Medicine and Health Science to conduct the research with a protocol No 051/2021. A formal letter was submitted to FHCSH and UGSH, informed verbal consents were obtained from the study participants after clearly introducing the purpose of the study. The respondents' right to refuse or withdraw from participating in the interview at any time was fully respected and the information provided by each respondent was kept confidential by making each questionnaire coded and not sharing personal information of any patient to the third party.

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## Patient and Public Involvement

Patients or the public WERE NOT involved in the design, or conduct, or reporting, or dissemination plans of our research.

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