

# PATIENT'S PERCEPTIONS OF ANTI-CANCER CHEMOTHERAPY SIDE EFFECTS AND ADHERENCE ON TREATMENT AT MBARARA REGIONAL REFERRAL HOSPITAL.

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## Abstract

### Background:

Chemotherapy is one of the most common treatment modalities for cancer. However, despite the benefits of indicated chemotherapy, the side effects and toxicities of the treatment frequently affect the patient's quality of life (QOL) and hence adherence to the treatment. The study aimed to examine the patient's perception of the anti-cancer chemotherapy side effects and adherence to treatment at MRRH

### Methodology:

The study utilized a descriptive qualitative design. It involved 40-60 minute in-depth interviews with 10 participants who had undergone chemotherapy treatment to understand their perceptions and their treatment adherence. Inductive thematic data analysis was used to generate themes and categories.

### Results:

The following themes and categories emerged: Benefits [helpful, feeling good, believed getting better], and perceived severity [chemotherapy side effects, frustration, pain, and fear of death].

### Conclusion:

The perceived severity of the chemotherapy had a considerable impact on the patients quality of life. Despite these side effects experienced by most of the participants, the benefits of chemotherapy and considerable support from staff influenced the participants to adhere to treatment.

### Recommendations:

There is a need for health workers to continue providing the necessary information about the disease, the drugs, the course of treatment, and the prognosis to improve patient acceptance of the chemotherapy.

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## 1. Background of the study

Anti-cancer Chemotherapy is one of the common treatment modalities for cancer (Dohler et

al., 2011). It is used to shrink tumors before radiation therapy or surgery, targeting cells that grow and divide quickly (Cancer Research U K (2017)). However, it can also impact on healthy cells that are constantly dividing such as those of hair and skin, bone marrow, and the lining of the digestive tract (Ricevuto E et al., 2010, Bruce., 2016)

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In a study conducted by Wampaalu et al., (2016) to explore experiences of patients undergoing chemotherapy treatment at the Uganda Cancer Institute (UCI) in Kampala, the most common side effects mentioned were loss of hair, digestion disturbances, depression, memory loss and fever. Negative perceptions about the chemotherapy side effects are associated with poor treatment outcomes, psychosocial distress and reduced quality of life (Verbrugghe, et al., 2013, Teker et al., 2015) this increases the risk of noncompliance and interruption or discontinuation of chemotherapy (Benavente & Costa., 2018) this reduces the effectiveness of chemotherapy and reduces survival (Ross et al., 2018).

In view of the frequent occurrence of side effects and toxicities after chemotherapy treatment, understanding of patient's perceptions is critical to achieving better patient outcomes (Given et al., 2011) and may influence their willingness to adhere to treatment protocol (Henry, et al., 2016, Abdel-Razaq et al., 2017).

## 2. Methodology

### 2.1. Study design:

The study utilized a descriptive qualitative design. It involved in-depth interviews with participants who had undergone chemotherapy to understand their perceptions, beliefs, and experiences of chemotherapy, and to understand how they adhered to treatment.

### 2.2. Study site:

This study was done at the Cancer unit (inpatient and outpatient) of MRRH. The hospital is 260 kilometers southwest of Kampala. MRRH has a 600-bed capacity for a catchment population of over 5,000,000 people in Southwestern Uganda and the neighboring countries. MRRH established the Cancer unit in 2011 to provide both pediatric and adult care for cancer patients. The adult cancer ward was built to have a 12-bed capacity for inpatients but currently, to meet the greater need, it has since increased to 20 beds.

The most common cancers include cervical cancer (30%), Kaposi's sarcoma (19%), breast cancer (10%), lymphomas (6%), and prostate cancer (4%). The adult cancer unit receives between 10 and 20 patients daily for chemotherapy. Patients who require more than one day of consecutive doses of chemotherapy are admitted to the ward, and those who receive one day of chemotherapy are usually treated as outpatients, receiving chemotherapy and returning home to return on the next appointment according to their scheduled chemotherapy. Most of the patients receive a minimum of six cycles of chemotherapy for 6 months. MRRH was chosen as the research site because it's the only medical facility in southwestern Uganda that offers chemotherapy services for both inpatients and outpatients.

### 2.3. Study Population:

The population included both females and males aged 18 years and above who had received chemotherapy or were currently receiving chemotherapy at the adult cancer unit.

### 2.4. Inclusion Criteria:

- All patients 18 years and older
- A patient who had previously received a minimum of one cycle of chemotherapy
- Those who can participate in the interviews and provide information about their perceptions of receiving chemotherapy.
- Those who consent to take part in the study.

### 2.5. Exclusion Criteria:

- Patients receiving adjuvant chemotherapy alone.
- Patients receiving any other treatment modality of cancer like surgery, or radiotherapy in addition to chemotherapy.

## 2.6. Sampling:

Purposive sampling strategy was used to identify patients to enroll in the study.

The effort was made to include female and male individuals, people with a variety of educational levels, different economic levels, a variety of cancer diagnoses, and those living in both urban and rural environments.

## 2.7. Data Collection

After receiving ethical approval from the Faculty Research Ethics Committee (FREC), the Research Ethics Committee (REC), and administrative clearance from the Hospital Director of MRRH, the researcher contacted the Head of the Cancer Unit and notified the Nurse in charge about the study. Individuals who had received chemotherapy or were currently receiving chemotherapy were selected for the interview. The study's purpose was explained to the participants, and verbal and written consent was obtained. A time convenient to the patient was selected for the interview at the clinic or hospital unit. The participants were interviewed after they had been seen by an oncologist and waiting to receive a cycle of chemotherapy infusion. They were interviewed in a comfortable place where there was no interruption and privacy was guaranteed. An in-depth interview was conducted by the principal researcher. The participants were engaged in a probing conversation using a semi-structured interview guide lasting between 40 and 60 minutes. The research assistant was fluent in the languages spoken in the local area. She was trained in the conduct of the research, how to complete the interview, how to obtain informed consent, how to record the information, and how to maintain confidentiality. The research assistant also took notes and captured the non-verbal communication in the interview.

The interviews were audio recorded to ensure that all that is said by the participant is captured. The interviews were done in the local language translated into English and then translated back into the local language to ensure credibility. All interviews were transcribed verbatim. Data saturation was reached at 10 participants. The

interview data was reviewed as it was completed to maximize obtaining the data and determining information saturation.

## 2.8. Data management:

The transcripts and the audio recordings were safely stored under lock and key or in a password-protected computer, and no unauthorized person was allowed to access the files to maintain the confidentiality of the information.

## 2.9. Data analysis:

Thematic analysis was done. The data from the recording was transcribed verbatim if it was in English. If the recording was in the local language, it was first translated into English and then transcribed verbatim. The recordings were listened to several times to appreciate the content. Then the transcribed data was read and re-read to identify the common issues that recur. The material was reviewed and the concept was identified. The concepts were organized into major themes that summarize the content. The data collected was reviewed as the interviews were completed. This preliminary analysis was to help to shape the later data being collected and to give feedback to interviewers.

## 2.10. Establishing trustworthiness:

Trustworthiness in this research was achieved by establishing four-dimension criteria credibility, dependability, transferability, and confirmability. (Lincoln & Guba 1985)

**Credibility:** This refers to how true and accurate the findings are. Credibility was enhanced by interviewing the participants using open-ended questions and responses were provided in the participants' vernacular and the interviewer engaged the participants for a period of 30 to 40 minutes in a conversation. The interview guide was reviewed by nurses and doctors working in the Cancer Unit and the research supervisor.

**Dependability:** This refers to the stability or consistency of the inquiry processes used over time. A dependability audit was done in which an independent auditor reviewed the activities of

the study ( this was recorded in an audit trail of field notes of data collection, and reports).

**Transferability:** means the extent to which results of the study's findings apply to other similar situations, similar populations, and similar phenomena. The participants were interviewed until data saturation was achieved.

**Confirmability:** To extend the confidence that the results would be confirmed or corroborated by other researchers. This was ensured by documenting the procedures for checking and rechecking data throughout the study. The literature review served as a source of confirmability.

**Ethical consideration:** Ethical approval was sought from the Faculty Research Committee and Institutional Research Committee of Mbarara University of Science and Technology. Administrative clearance was obtained from the Director of MRRH. The purpose and benefits of the study were explained to the Key Informants. They were told before the interview, they have the right to refuse participation, could leave the study at any time, and could select not to answer a question without any penalty. They understood that their participation or deciding not to participate in the study would in no way interfere with the medical treatment they were receiving. The participants were guaranteed anonymity and confidentiality. The individual participating in the interview was asked to sign a consent form before they participated.

### 3. Results

#### 3.1. Demographic characteristics

We interviewed 10 participants in this study, four females and six males aged between 18 and 83 years, six were married with children and four were single (one female and three males). Two of the participants were formally employed. Of the participants, six were Catholics, two were Protestants and one was Muslim (see Table 1).

#### 3.2. Theme Development

Two themes emerged from the numerous identified categories and were then organized by using the conceptual framework. The themes are an

effort to explore the patient's perceptions of anti-cancer chemotherapy side effects and their adherence to treatment at MRRH.

#### 3.3. Theme 1: Benefits of chemotherapy

This theme emerged from three categories namely chemotherapy is helpful, makes you feel better, and the belief that you can get better. Participants felt chemotherapy would help reduce their pain. They also believed that when they received chemotherapy they would improve and live longer. Several understood that the benefit of chemotherapy was not to cure but to improve their remaining quality of life. Others noted that the medication made them more energetic, increased their physical activity, and made them feel strong and able to participate in family and community activities.

*"This chemotherapy has helped me so much; it has made me feel better which I think is a good thing..." [ID-06-JO]*

*"...I am getting the treatment that the chemotherapy they give me is to help reduce the pain that I have so that I can live for some time, but I will not get cured" [IDI-10]*

*"Sometimes I may wake up and I feel I am a bit strong and feeling good because of the medicines but there are times when I feel not well as if I do not even want to leave my bed" [08-NG]*

*"...if there was no chemotherapy treatment some of us would be dead by now..." [ID-06-JO]*

*"...so, to me the benefit that I see since 2015 and now it is 2019, I feel I have lived more than what I expected and all that is because of the medicine" [08-NG]*

*"... Yes, I do believe I will get healed." [05-JO].*

#### 3.4. Theme 2: Perceived Severity

This theme emerged from identifying chemotherapy side effects, frustration, pain, and fear of death. The participants believed that chemotherapy reduced their appetite, and had vomiting and diarrhea causing them to both eat and drink less. This they noted frequently resulted in weight loss. The participants also noted

Table 1: Demographic Characteristics of the participants

Characteristic	No of participants
Age	18-29 N= 3
	30-39 N=1
	40-49 N=2
	50-59 N=2
	60+ N= 2
Gender	Male N=6
	Female N=4
Marital Status	Married N=6
	Not Married N=4
Formal Employment	N= 2
Religion	Catholic N=6
	Protestant N=2
	Muslim N=1

Table 2: Perception of anti-cancer Chemotherapy side effects

Themes	Categories
1 Benefits	Helpful Feeling good Believing in getting better
2 Perceived Severity	Chemotherapy side effects Frustration Pain Fear of Death

that chemotherapy affected their feeling of well-being, and inability to have sexual relationships. Some noted frequent headaches, severe and incapacitating pain, and the participant’s inability to work or do their normal daily activities.

“The part of not eating at all, neither can you drink anything at all that is the most serious effect”. [ID-06-JO]

“The appetite is completely gone, and the body completely becomes useless”. [ID-06-JO]

“These drugs after you have used them, you get a serious headache, sometimes you feel like some fever....” [09-NG]

“I have lost weight and become so small... ” [08-NG]

“... Yeah and I was feeling stressed and hating myself and I knew that I was going to die so quickly. What was hurting was that I was going

to die without leaving my family anywhere.....”. [09-NG]

“... My family also gets challenged by my condition as a cancer patient because I am no longer productive like the way I used to be. I cannot manage to do the things that I used to do. As long as you are a cancer patient, you cease to be productive, you are always just there sitting and sleeping..... all my activities come to stand still,” [09-NG]

“..... you start feeling a lot of pain and scratch them as if you want to pluck and throw them away.....” [09-NG]

“But this chemotherapy also had its challenges, my nails got plucked out I think you can see my toes; my hair was all gone, and vomiting was too much as well.” [ID-06-JO]

“Yeah, and I was feeling stressed and hating

*myself and I knew that I was going to die so quickly. . . .” [09-NG]*

#### **4. Discussion:**

The study enrolled 10 participants, 4 females and 6 males aged 18 to 83 years, 6 were married with children and 4 singles. 7 were Catholics, 2 were protestants and one was a Muslim. These participants perceived the side of chemotherapy differently. These findings correlate with studies done by Gurung, & Pandey (2015) in Nepal. Their findings showed that the perceptions of the side effects of chemotherapy were not the same from individual to individual, regardless of the age, sex ethnicity or religion. The findings of this research and for the previous researches agree with the HBM as described by Rosenstock (1988). The model suggested that individual characteristics of participants (like demographics, psychosocial, and structural variables) affected health-related behaviours indirectly by affecting perceived seriousness, susceptibility, benefits, and barriers (Rosenstock, 1988).

##### *4.1. Perceptions of anti-cancer chemotherapy side effects:*

###### *4.1.1. Benefits:*

Participants' perception of chemotherapy was beneficial because they felt it helped them to feel better and reduce pain and believed they would get better. This finding concurs with the research done by Jacobs and colleagues (2017) in studies conducted in the USA in which they examined patients' perceptions that increased the likelihood of adherence to chemotherapy. They noted Improvement with QOL, decreased symptoms, decreased perceived burden of the disease, and satisfaction with the clinician's communication and skills were all perceived beneficial, and this increased adherence. There is a need for health workers to guide the patients before initiating chemotherapy. This will help foster acceptability of the treatment and therefore better outcomes.

###### *4.1.2. Perceived Severity*

Severity was expressed by most of the patients who received chemotherapy and experienced the

side effects. The most common side effects that were reported included severe vomiting and feeling nauseated, loss of appetite, change in skin colour, plucking of nails and general body weakness. These findings agree with researches conducted in Brazil, Benavente & Costa (2018) regarding chemotherapy treatment side effects. According to the findings, most participants focused on the negative experience side effects of chemotherapy. These were seen to contribute to non-adherence to chemotherapy and hence the abandonment of treatment. Also, in a qualitative study in Zambia ten in-depth interviews were conducted with women with advanced breast cancer. The women expressed extreme dissatisfaction about the side effects of fatigue, nausea, vomiting, anorexia, and alopecia, and how chemotherapy completely changed their appearance, their feminine role, and their lives. (Maree & Mulonda, 2015). Undergoing chemotherapy leads one to experience complications and frustrations and this will determine how one will endure and complete the prescribed cycles (Wampaalu et al., 2016). However, in this study no participant expressed nonadherence as a result of the side effects.

#### **5. Conclusion**

Patients' perceptions of chemotherapy side effects were seen as beneficial. The side effects were also perceived as dissatisfying because of complications, frustration, pain, and fear of dying. However, the side effects of chemotherapy in this group of participants did not affect adherence.

#### **6. Recommendation:**

There is a need for the health workers to continue providing the necessary information about the disease, the drugs, the course of treatment, and the prognosis to improve patient acceptance of the chemotherapy.

#### **7. List of Abbreviations.**

QOL: Quality of Life

UCI: Uganda Cancer Institute

WHO: World Health Organization  
MRRH: Mbarara Regional Referral Hospital  
CHEMO: Chemotherapy

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## 9. Conflict of interest:

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RN/BSN/MNS-CCN/PGDME. Am a diligently focused nurse with vast experience in both the clinical and classroom areas with an ability to develop strong connections with the community. Effective at multi-tasking while maintaining the end objective. My main focus now is sharing knowledge through pedagogical learning

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