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Experiences of patients undergoing chemotherapy - a qualitative study of adults attending Uganda Cancer Institute

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Abstract

Background: Cancer is a global public health challenge and how patients in countries with poor healthcare infrastructure experience cancer treatment is largely unknown.

Purpose: The objective of this study was to describe adult Ugandan cancer patients' experiences of undergoing chemotherapy treatment.

Methodology: Using a qualitative descriptive design, seven in-patients with varying cancer diagnoses at the Uganda Cancer Institute were interviewed about their experiences of undergoing chemotherapy treatment; the interviews were transcribed and analysed thematically.

Results: The analysis resulted in nine subthemes, which were categorized under three main themes: 'experiences related to the body', with the subthemes dry and sensitive skin, changes in eating and bowel habits, fever and feelings of abnormal body sensation; 'thoughts and feelings', with four subthemes reflecting the psychosocial impact of chemotherapy; and 'actively dealing with discomfort', with three subthemes describing how patients dealt with side effects, such as by sticking to a diet.

Conclusion: Receiving chemotherapy treatment is difficult, and the side effects negatively influenced patients' bodies and moods. Dealing actively with discomfort and accepting negative impacts in hope of a cure helped the participants manage the acute complications related to the treatment. We recommend the development of interventions to ease discomfort due to chemotherapy.

Keywords: Cancer, chemotherapy, experiences, nursing, qualitative

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Introduction

It is well-known that patients who are diagnosed with and treated for cancer may experience difficult emotional responses, in addition to physical discomfort. However, most of the studies analysing patients' experiences of cancer have been performed in high-income countries, and the situation for patients in low-income countries is largely unknown.

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The incidence of cancer on the African continent, with its 55 states, is expected to rise by more than 80% in the next 20 years due to demographic changes, e.g., lifestyle changes, increased life expectancy and the improved treatment of infectious diseases[1]. In sub- Saharan Africa, cancer mortality is high because of poor infrastructure, lack of healthcare workers, advanced stage at presentation, a dearth of treatment choices and poor compliance[2].

With this paper, we want contribute to the development of a body of knowledge in cancer healthcare delivery research by exploring patients' experiences of undergoing treatment in a low-income country, Uganda, which is situated in East Africa.

Chemotherapy is associated with a number of acute side effects, such as nausea and vomiting, loss of appetite, mucositis, diarrhoea, infections, fatigue and emotional distress[3-4]. Only two studies from East Africa have been found that describe patients' experiences of undergoing chemotherapy[5-6]. One of these publications studied Kenyan males by means of self-reported questionnaires and found that 93% of the participating men reported complaints regarding pain, inability to work and feeling miserable and that they expressed concerns regarding their families, health and work retardation[5]. The other publication had a mixed-methods design and investigated health-related quality of life among adult Tanzanians with cancer. According to the results, negative effects on social, role and physical function and overall health status and quality of life were reported, as well as a high level of problems, especially those associated with pain and financial difficulties. The participants did, however, report a relatively high level of emotional function[6].

The above-mentioned findings underscore the importance of focusing research on persons with cancer in areas where access to healthcare and treatment is a challenge. There is a great need to identify areas to be focused on in interventions that attempt to reduce the suffering in patients undergoing cancer treatment. Because no previous studies have been performed in Uganda, a qualitative approach was chosen to describe the experiences of patients undergoing chemotherapy treatment.

Methods

The study employed a qualitative, descriptive design and involved the thematic analysis of interviews with patients undergoing chemptherapy treatment. Such a design is, according to Sandelowski, theoretically based in naturalism and will likely stay as near to the data as possible [7-8].

Setting

The study was carried out at the Uganda Cancer Institute (UCI), a public cancer and training centre owned by the Uganda Ministry of Health, cofounded via international collaborations. It is the only specialized facility in the East African region serving Uganda, among other countries. The UCI offers inpatient and outpatient services free of charge to adults and children, a community cancer program to serve other parts of the country research and training. The available services include screening (cervix and breast), as well as treatment (limited surgery, radiotherapy and chemotherapy). The commonly prescribed chemotherapy treatment agents are bleomycin, cisplatin, vincristine, daunorubicin, docataxel and doxorubicin. At the time when the study was carried out, care for 100 inpatients was organised into two wards, one for children and one for adults. The most commonly diagnosed cancers at UCI are Kaposi's sarcoma (both sexes), cervical and breast cancers in females, prostate cancer in males and non-Hodgkin's lymphoma in children.

Sample

Adult inpatients fulfilling the following criteria were identified: spoke either Luganda (local language) or English, were >18 years old, were currently under chemotherapy treatment and were considered strong enough to participate in an interview. A purposeful sampling technique was employed to ensure that patients of both sexes and a variety of cancer types were included. The Chief Nursing Officer initially identified 15 patients who were at least halfway through their planned chemotherapy treatments and were deemed able to sit and talk. Just before data collection, the nurse reevaluated the physical and mental status of the potential participants and decided that eight of them should not to be approached, because they were receiving treatment or
were too weak. The remaining seven patients consented to participate in the study and were subsequently interviewed on the same day.

Procedure

The study was approved by the College of Health Sciences Institution Review Board (IRB). The purpose and procedures of the study were explained orally, in addition to handing out written information. Potential participants were informed that it was possible to withdraw from the study at any time and that such a decision would not impact their care; written informed consent was obtained.

Data collection

The first author (PW) conducted face-to-face interviews (approximately 25-45 minutes) in February 2011. An interview guide was developed covering the information received prior to treatment, experiences of undergoing chemotherapy treatment and coping with its negative effects. Probing and follow-up questions were used during the interviews. The interview guide was prepared in both English and the Luganda language to ensure that the same areas would be covered, regardless of what language was spoken. Before the start of the study, the interview guide was tested on patients undergoing cancer treatment to confirm that the questions were feasible and relevant.

Data analysis

The transcripts of the interviews were analysed using descriptive thematic analysis[9] via the following steps: (1) the transcribed text was repeatedly read to gain an overview; words and sentences having similar meanings were identified and coded. (2) Codes with similar meanings were classified into subthemes, which were further grouped into themes that reflected their central content. (3) During the analysis process, the codes and themes were discussed among the first author and co-authors (PW, RN) until a first agreement was reached. A similar analysis was also performed by the other three authors (LEE, LW, AN), and the results from both analyses were discussed and merged into a final organization of the findings.

Results

Four females and three males aged between 30 and 47 years (median 40) were interviewed. Six of the patients were married, and one was single; all patients had children. Four of them were currently employed, while three were unemployed. Participants represented four diagnoses: Kaposi's sarcoma, n=4; AIDS-related Hodgkin's disease, n=1; penile cancer, n=1 and acute lymphocytic leukemia, n=1. The thematic analysis of the interviews resulted in three themes: 'experiences related to the body', 'thoughts and feelings' and 'dealing with discomfort'. The themes are further described below.

Experiences related to the body

The theme 'experiences related to body' included four subthemes: changes in eating and bowel habits, dry and sensitive skin, fever and feelings of abnormal body sensations, most of which could be related to side effects.

The experiences of changes in eating and bowel habits were reported to be difficulty in eating and keeping food down, as well as episodes of diarrhoea, as illustrated in the following statement: "I had an episode of abnormal sounds in my stomach, which was accompanied by diarrhoea and mild bloody urine that started the same day" patient D, male, 45 years. Furthermore, loss of appetite was frequently described, as in the following quote:

"What they told me about losing appetite is true; when I try to force myself to eat, at times, I get hiccups and a feeling of incompletely swallowed tablets along the throat. The feeling of tablets along the throat makes it hard to swallow" [patient A, female, 45 years].

Dry and sensitive skin was typically described as itching.

"My skin used to itch, and I would experience tingling sensations all over my body, especially when they just had injected the chemotherapy. This could make me crazy, and I felt like shouting for help to get attention and empathy" [patient F, male, 40 years].

Having a fever was experienced as exhaustion, including both freezing and being warm. Experiences of abnormal body sensations were expressed in various ways. Patient C (female, 35 years) described this as follows: "… numbness and paralysis of different parts of my body, especially my teeth in the jaw. It feels like my teeth have been removed, I do not feel the teeth in my jaw." Discomfort when chemotherapy agents entered the blood vessels was also described. This could be described in terms of experiencing irritation, while others described it as almost unbearable.

Thoughts and feelings

The theme 'thoughts and feelings' included four subthemes: worry and fright, loss of one's previous lifestyle, patience and acceptance and happiness to receive treatment. Almost all participants expressed that they needed some time to get used to and accept their chemotherapy treatment. Patients commonly expressed that they were scared when told about their diagnosis and that they questioned why this had happened to them. Financing was mentioned by several patients when describing what worried them, as exemplified by Patient A (female, 45 years):"Other things I rarely eat because most of the time, I don't have money. I have much sorrow and depressed mood; at times, I hide and cry because of my children's

fees." Leaving home for the next treatment cycle was also described as distressing by Patient A (female, 45 years): "Towards the appointed day for my reporting to the Institute, I felt worried and scared and downhearted because I feared the side effects of the chemotherapy. I was considering what I would have to go through."

Many participants mentioned that they had given up on what they used to enjoy, such as drinking alcohol, smoking and strenuous activities, because receiving treatment made these impossible. While some participants had put their daily activities on hold after having gone through some chemotherapy cycles, Patient F (male, 40 years) was able to narrate the changes in his life with a smile: "I came in a wheelchair, but when the first six cycles of the chemotherapy were completed, I could drive my car to and from Kabale."

Negative effects were often accepted because there were no other alternatives: "I decided to accept it because there are no other alternatives. I like the chemotherapy on the condition that there are no any other alternatives for my condition" (Patient E, male 47 years). Despite negative experiences during chemotherapy, many of the interviewed patients said that they were happy that it was possible to treat their cancer.

Actively dealing with discomfort

The theme 'actively dealing with discomfort' included three subthemes describing how patients handle chemotherapy treatment: a balanced diet, the use of supplementary drugs, and physical exercise and rest. Patients generally described that before the start of treatment, they had received recommendations from nurses and physicians regarding how to prevent and reduce the negative impact of treatment via self-care actions. Such recommendations included instructions regarding diet and drugs: "I follow the instructions I received from the nurse; for example, I shouldn't smoke or take alcohol" (Patient E, male, 47 years). Others, who had not understood the information, sought clarity: "When I sought education from the doctor, I got used to the side effects after understanding that they were actually side effects and learned to stand them" (Patient E, male, 47 years).

Almost all participants reported using diet to reduce the impact of the side effects. Participants expressed that they thought that a good diet helped them to restore their blood because one of the side effects of chemotherapy is anaemia. Some participants reported adding fruits and vegetables to their diet. One of the participants described water as helpful in maintaining a moist and smooth skin texture and said that whenever she drank too little water, her skin became pale and dry.

Some participants received additional treatment from other institutions, such as the AIDS Support Organization (TASO), which helped them to reduce the side effects of chemotherapy, such as sores in the mouth and diarrhoea.

Some participants reported engaging in exercises, in addition to their improved daily diet, which they said reduced some of the impact of the pain and worry. Simple exercises included doing normal daily activities or going for a walk. One participant narrated, "Walking helps me to relieve tension in the legs and also brings the swelling of the legs back to normal" (Patient G, female, 30 years).

Discussion

Receiving chemotherapy treatment was perceived as difficult, and the experienced side effects negatively influenced patients' bodies and moods. Dealing actively with discomfort and accepting negative impacts in hope of a cure helped the participants to manage the acute complications of their chemotherapy. Several strategies to actively deal with the experienced discomfort were described, which gave the overall impression that the patients coped quite successfully.

The negative experiences described in the theme 'experiences related to the body' reflect typical side effects of chemotherapy, such as fatigue, diarrhoea and loss of appetite, as well as the inability to perform daily activities during the initial days of treatment, all of which are known to compromise patients' quality of life[10-11]. The described experiences are partly in line with the findings from the two existing studies of cancer patients undergoing chemotherapy treatment in East Africa[5-6]. The study from Tanzania revealed that being diagnosed with and undergoing treatment for cancer often had a strong impact on health-related quality of life, causing multiple concerns regarding the need for care and support. The patients in the Tanzanian study also described some un-

met needs, such as concerns regarding a lack of hygiene articles and pain relief, which were not mentioned in the present study[6].

Overall, the physical and psychosocial problems and the coping strategies patients used to handle problems, reflected in the theme 'thoughts and feelings', are similar to those reported in high-income countries, e.g., acceptance, relaxation and distraction[11]. The interviewed patients described how they dealt with the side effects of chemotherapy in a number of ways. The findings presented in the theme 'actively dealing with discomfort' are in line with those of a study carried out in South Africa[12], which revealed that physical activity exerted a positive effect on mood and also alleviated symptoms of psychological distress in cancer patients. Furthermore, in our study, patients shared that they took supplementary drugs to reduce or prevent the impact of side effects; however, they did not appear to clearly understand what supplementary drugs they took or what effects they had. Furthermore, some described taking drugs to have effects on other diseases, such as HIV/AIDS, and they could not differentiate between drugs for reducing the side effects of chemotherapy and those for other diseases. Patients receiving supplementary medication while undergoing chemotherapy appeared to need extended support to understand the effects and intake timing of the prescribed medication.

The fact that almost all participants described how they actively dealt with the discomfort and negative experiences of side effects may be related to the information they received prior to start of the treatment. Based on the results shown in the theme 'actively dealing with discomfort', information prior to and while undergoing treatment appeared to have a positive impact on the care of patients. At the UCI, all patients receive counselling from nurses before the start of chemotherapy to help them cope with side effects when they occur. The nurses' suggestions typically cover the importance of eating a balanced diet, accepting the current situation and being tolerant, performing simple exercises and using supplementary drugs when such are prescribed and available. This is believed to have had an impact on patients' physical and psychological states because many of the patients stated that they had been told about the side effects of chemotherapy, which made the symptoms easier to bear. This is in line with other studies that have found that the education of cancer patients is associated with a greater degree of satisfaction with treatment choices and an improved ability to cope when receiving treatment[13-14]. In addition to information from healthcare professionals, some participants may have shared the information about side effects with other patients because a number of them had been on the ward for some time. Peer support has been shown to be useful in psycho-educational support programmes targeting patients with cancer[15].

Methodological considerations

This study was carried out by researchers with backgrounds in various cultural contexts. Furthermore, the authors who analysed the transcribed data included senior researchers with experience in cancer care and qualitative research methods. The researchers had experience in Uganda as well as in countries outside Africa.

Issues of trustworthiness were examined via the criteria credibility, dependability and transferability[16]. Credibility was achieved by selecting patients of both sexes with various cancer diagnoses to reflect the patients receiving chemotherapy at the hospital. The topics and main questions were the same for all participants, but the posing and timing of the questions and follow-up questions differed according to the relationship and dialogue.

The transcribed interviews were initially analysed by two independent constellations within the group of authors. Later, the two constellations discussed the findings to reach an agreement. Efforts were also made to identify quotations from the transcribed text to illustrate themes and subthemes. Dependability was enhanced by exploring the same areas among all participants and discussing the analysis and results among authors. Transferability was addressed via a careful and detailed description of the context and recruitment process, the procedure for data collection and analysis and the presentation of the results.

One potential weakness of the study is the low number of participants. We do not know whether a larger sample would have allowed a greater understanding of how chemotherapy treatment is experienced. Nevertheless, this is the first qualitative study carried out investigating cancer patients' experiences in Uganda.

Conclusion

Receiving chemotherapy treatment was not easy, and the side effects participants experienced had a negative impact on their bodies and moods. Dealing actively with discomfort and accepting negative impacts in hope of a cure helped the participants manage the acute complications of their chemotherapy. We recommend that interventions to ease discomfort due to chemotherapy be developed and tested in Uganda.

Conflict of interest

None to declare.

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