Assessment of Psychological Distress and Emotional Well Being After Cancer Diagnosis in Patients Aged 20 to 50 Years at University Teaching Hospital, Lusaka, Zambia

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Abstract

Background: Cancer is a disease characterized by abnormal growth of cells and can develop anywhere in the body. Treatment options depend on the disease stage at presentation and most cancers are curable when detected early. The disease burden, the tumor itself and its treatment options can put patients at increased risk of psychological distress and mental health disorders.

Goal/General Objective: Was to describe emotional and personal experiences in patients diagnosed with cancer, and to find out the most common mental health disorders that arises after the diagnosis of cancer is made.

Specific Aims/Objectives: Was to assess psychological distress and emotional well-being in patients aged 20 - 50 years.

Methods: The study was conducted at Cancer Disease Hospital at the University Teaching Hospital. This was a qualitative study targeting cancer patients aged 20 - 50 years old. Direct questions (With a translator(s) to Nyanja, Bemba, Tonga etc. as required) and Questionnaires were used for literate patients to collect data.

Data Analysis: Data analysis was done by manual analysis using the content analysis approach.

Significance of the project: Studies have discovered that patients develop emotional distress and mental health disorders after cancer diagnosis therefore, a better understanding of cancer patient's psychosocial aspects may improve the quality of care provided in clinical settings.

Ethics and Regulatory Approvals: The study was conducted in accordance with the three basic ethical principles, namely respect for person, beneficence and justice. The study was carried out following approval from an established research ethical committee.

Conclusion: Most of the patients that were newly diagnosed with cancer suffer from one or more psychological disorders and feelings of helplessness with depression being the commonest. These negatively affect the outcome of treatment in the long run.

Keywords: Psychological Distress; Emotional Well Being; Cancer Diagnosis

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Abbreviations

C.D.H: Cancer Disease Hospital; CHEMO: Chemotherapy; PANAS: Positive and Negative Affect Schedule; RAD: Radiation; U.T.H: University Teaching Hospital; W.H.O: World Health Organisation; RVD-R: Retroviral Disease Reactive

Introduction

Cancer is a disease characterized by abnormal and uncontrolled growth of cells that can affect any part of the body [1]. Cancer is a major global health concern. It is the third leading cause of death globally and is responsible for an estimated 9.6 million deaths in 2018, despite improvements in treatments options for different cancers. Cancer signs and symptoms depend on the specific type, making diagnosis and treatment to be unique for each cancer and also considering different patient's individual factors. According to the Zambia National Cancer Control Strategic plan (2016) [2], the most commonly diagnosed cancers in men are Kaposi's sarcoma, non-Hodgkin's lymphoma, prostate cancer, esophageal cancer and colorectal cancer. In females the most commonly diagnosed cancers are cervical cancer, breast cancer, Kaposi's sarcoma, esophageal cancer and colorectal cancer. The common risk for developing most of these cancers is advanced age that is at least above 50 years old, but it is not uncommon to find these cancers in patients who are way younger.

Cancer is a disease that can potentially affect anyone, rich, poor, educated and uneducated alike and unfortunately cancer and can be found across all age group. In general, cancers can have many causes, ranging from genetic mutations to behavioral risk factors and environmental exposures to carcinogens [1]. Mental disorders such as anxiety and depression can cause activation in the hypothalamic-pituitary-adrenal axis and autonomic nervous system with corresponding deregulation of circadian cortisol rhythm and release of catecholamine and this whole cascade on its own have negative impacts on tumor progression and survival leading to early mortality [3]. Moreover, cancer treatment options (chemotherapy, radiation and surgeries) have a great impact in a patient's life and making the decision toward the treatment option can greatly affect an individual emotional and psychological well-being. A study conducted at Oncology Institute of Istanbul University in Turkey found that incidence of psychological disorders being diagnosed for the first time in patients with cancers was very high (30 - 60%), with approximately 40% fulfilling the diagnostic criteria for psychiatric disorders. The most encountered mental health problems were adjustment disorders, anxiety disorder, mood disorders, delusional disorders, depressive symptoms and major depression [4].

The World Health Organization (WHO) defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. Health therefore encompasses physical and mental wellbeing [5]. Mental wellbeing is closely affiliated with the concept of quality of life, together with an absence of current mental health problems and significant emotional distress. Both distress and depression assessment are important not just for mental health professionals but also for cancer clinicians, making psychooncology to be an important part of treatment [6].

Statement of the problem

In Zambia the majority of cancer patients are young adults (at least 20 - 50 years old) and they present with advanced disease [7]. Most of these patients are from poor socio-economic status who may not have enough money for diagnostic tests and treatment options. This puts them at an increased risk of psychological distress from the fear of death. Most of these patients are not assessed for psychological distress leaving a huge gap between oncology and psychiatry [6].

This study therefore explored individuals' perceptions of their diagnosis and psychological distress that come about after the diagnosis of cancer is made. It also explored the emotions of younger patients (20 - 50 years old) who may have had dreams and ambitions with these future plans that could be potentially shattered following cancer diagnosis.

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Study rationale/justification

Although other studies have been conducted, this dissertation is the first study to quantitatively examine the mental health aspect and emotional burden of cancer in young adults in Zambia. The findings of this study would benefit oncology practice, policy, research, and education from evidence based-information. A better understanding of cancer patient's psychosocial aspects may improve the quality of care provided in clinical settings. Clinical practice can benefit from a fuller understanding of foundational knowledge about the impact of cancer diagnosis and its treatment as being experienced by cancer patients.

Research question

a) What effect does cancer diagnosis have on the psychological and emotional well-being in young adult cancer patients?

b) What are the mental disorders commonly encountered for the first time in young adult cancer patients?

Research Objective

General objective

To assess psychological distress and emotional well-being arising after cancer diagnosis in patients aged 20 to 50 years old at UTH, Lusaka, Zambia.

Specific objectives

a) To identify and describe emotional and personal experiences of young patients diagnosed with cancer in Zambia.

b) To identify first-time mental health disorders that young patients develop after the diagnosis of cancer is made in Zambia.

c) To establish and describe the psychosocial and cancer-related quality of life experiences of cancer patients in Zambia.

Literature Review

Cancer and distress

Global context

A study conducted at the Oncology Institute of Istanbul University in Turkey, to assess characteristics and risk factors for common psychiatric disorders in patients with cancer seeking help for mental health found that the incidence of psychiatric disorder was at 97.5% of all the participants. The psychiatric disorders found amongst these patients were adjustment disorders, depression and major depressive disorders, mood disorders, anxiety disorders, organic brain syndrome, personality disorders, delusional disorders and insomnia [4].

Prakash., *et al.* [8] in India, carried out a study to find out the spectrum of mental disorders in cancer patients and also to find the association between sociodemographic variables and stage of tumor, treatment modality with the various psychological problems among cancer patients. They found out psychological problems were highest amongst patients from rural areas and among females patients compared to males. Highest anxiety and somatization was found among patients in stage II and depression in stage IV cancer. Among treatment modalities highest anxiety was found among patients under chemotherapy treatment, somatization among patients under both chemotherapy and radiotherapy and depression among patients undergoing radiotherapy.

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A qualitative study was conducted in a family practice settings at University of Tartu in Estonia, where 10 cancer patients were interviewed to express their personal experiences with cancer care. Cancer patients experienced a lack of information concerning their cancer and its treatment, and they also perceived that the cancer treatment they were receiving made them to suffer [9].

Another study was carried to assess psychological distress among cancer patients undergoing radiotherapy in Saudi Arabia. They found out that patient's type of cancer was significantly associated with the level of emotional distress, and depressive symptoms which had significant implications to their adherence for treatment and patient's outcome [10].

Zambian context

A study was done which explored experiences of adolescents aged between 12 and 18 years living with cancer in Zambia, focusing on their physical and psychosocial problems. Findings of the study showed that these adolescent have difficulties in coping with the new diagnosis and majority reported aching of different body parts, feeling weak, and medicine and treatment exhaustion. Most of them also expressed helplessness and shock, loneliness, self-pity and loss of social ties [11].

Another study done focusing on Zambian women's experiences of advanced breast cancer, and the mean age of the participants was 48.2 years with 7/10 of the patients having stage IV breast cancer, found out most women did not know the early signs and symptoms of breast cancer leading to advanced disease at diagnosis, other experienced shock at the treatment option of surgical removal of their breast, and some associated breast cancer with a death sentence [12].

Context of emotional well-being of cancer patients undergoing surgeries, chemotherapy and radiotherapy

Literature showed that most patients experienced different emotions and thoughts regarding their treatment options:

a) Thoughts and fears about cancer including: fear of recurrence; anxiety about the future; isolation, fear of death and intrusive or avoidance thoughts about cancer.

b) Fear and anxiety of dying during major surgical procedures

c) Psychological consequences of treatment including fear of the possibility of early menopause; late or longer-term effects such as weaknesses and fatigue.

d) Returning to normal including: dealing with changes to identity; body image; returning to work; and uncertainty about health and effects of treatment.

e) Sexuality and fertility including: decreased libido; erection and ejaculatory difficulties; reduced frequency of sexual intercourse; anxiety about future infertility; and decreased interest in having a child.

f) Follow up including: ambivalence about discontinuing treatment; fear of future; follow up appointments; and longer-term effects of treatment.

g) Impact of cancer on family and friends who have to take care of the patients.

h) Financial implications including: a loss of income and assets during treatment and ongoing challenges obtaining insurance [8].

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Research Methodology

The study took about two months to be completed from the time it was authorized by the Mulungushi University School of Medicine and health sciences Research Ethics Committee (MUSoMHS-REC). This time was divided into two weeks of data collection and one month two weeks of data analysis and conclusion with the supervisors.

Study site and population

The study was conducted at the University Teaching Hospital (UTH), Cancer Diseases Hospital (CDH). All patients meeting the eligibility criteria, male and female subjects were considered.

Study design

To achieve the objectives of the study, a non-experimental and descriptive study design was used. Qualitative data involving obtaining raw data from research subjects was used to asses for the Psychological distress and emotional well-being after the diagnosis of cancer is made in patients between 20-50 years old at UTH, Lusaka, Zambia.

Eligibility criteria

Inclusion criteria:

    i.   Patients with a histological diagnosis of cancer.

    ii.   Patients aged 20 - 50 years old willing to participate in the study.

Exclusion criteria:

    i.   Patient who had a pre-existing psychiatric disorder before getting the diagnosis of cancer.

    ii.   Patients not willing to participate in the study.

Selection of participants and sampling method

A simple random sampling technique was used to acquire the required sample size. Using CDH registry book, on a designated date to collect data, a list of patients between 20 - 50 years old (males and females mixed) was made and the patients were picked at random. Every 5th number on that specific day was picked, making a total of three patients interviewed per day. This was done to make sure that each participant had an equal and fair chance to be picked and to make study unbiased.

Sample size estimation

The study population is about 15 new patients on average as daily cancer attendances at UTH, CDH.

Sample size is calculated using the Slovin's formula:

$n = N/1 + Ne^2$

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Where:

n- Is the sample size

N is the total population of cancer patients seen at UTH, CDH every week

e- Refer to the error expected with 95% confidence interval which is 0.05

n =15 participants.

Variable of interest

- Self-esteem

- Cancer pain

- Psychiatric disorder due to a paraneoplastic syndrome

- Prophylactic cognitive behavioral therapy.

Data collection plans and tools

Primary data was collected through a structured questionnaire and direct recorded and transcribed interviews. The questionnaires consisted of questions that enveloped all the intended aspects on cancer status.

With the help of an assistant, patients were helped in understanding questionnaires and answering questions accordingly. Subjects who were unable to read and write, a translator was used to translate from English to Nyanja and Bemba where ever applicable using the same standardized questionnaires used in literate subjects.

The data was collected on the first day of the week (Monday), third day (Wednesday) and fifth day (Friday) of the week for a total of two weeks.

The data collection tool was not pre-tested, as to get raw data from patients themselves without any prior expectations. Descriptive data collection method was used involving using tables and standardized questionnaires was used to conduct the study.

Patient's files were also be used to collect data.

Data management and analysis

The questionnaires were coded accordingly for easy data processing. Information collected from the questionnaires was transcribed and recorded interviews was then manually analysed to see which themes are common and then discussed as per theme.

Ethical considerations

Ethical approval was sought out from Mulungushi University School of Medicine and health sciences Research Ethics Committee (MU-SoMHS-REC). Permission to carry out the research was sought out from Cavendish University Zambia, School of Medicine, University teaching hospital the administrative body and hospital staffs.

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No names were used to identify the participants; rather they were identified with unique numbers only known by the interviewer. Participants were reassured on maintenance of anonymity and confidentiality that the study would follow the three basic ethical principles of respect for persons, beneficence and justice. All participants were required to give verbal consent before participating in the research and there was no financial gain or rewards given to participants. The research was strictly conducted via questionnaire, interviews and patient files. There were no interventions carried out during the research. Information obtained during the research was confidential and kept under lock and key.

Results and Data Analysis

20-25	25-30	30-40	40-50
2	3	4	6
Total: 15 participants			

Table 1: Age.

The table shows the number of people according to age distribution. The total number of participants was 15 participants, of which most were in the age range of 40 - 60 and 30 - 40 respectively. The age range with the lowest number was 20 - 25 which only had 2 people. This showed that the older age group was more prone to getting cancer as compared to the younger ones.

Single	Married	Divorced	Widowed
2	6	4	3

Table 2: Marital status.

The table above shows marital status of the participants, of which 6 were married, 4 were divorced and 3 were widowed. Only two from the total sample size of 15 were single. This was very important as it helped show whether the participants had a spouse to support them as they battle with the disease and its treatment.

Grade 7	Grade 10	Grade 12	Diploma	Degree
2	3	5	3	2

Table 3: Level of education.

The table above shows the highest level of education attained by each of the participants. There were a total of 5 who had grade 12 as their highest level of education. While 2 had a degree, 3 a diploma and 3 grade 10. The least number was 2 who had grade 7 as their highest level of education.

Unemployed	Full Time	Part Time	Student	Retired	Home Maker	Disabled
4	1	2	1	6	0	1

Table 4: Employment status.

The table above shows employment status of the participants. From the table above most of the participants were retired, while 4 were unemployed and 3 were employed. There was only 1 student from the total sample size. Most of the participants were either retired or currently unemployed owing to their long term illness.

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< 1 Months	1 - 6 Months	7 - 12 Months	> 12 Months
2	3	6	4

Table 5: *Duration since diagnosis of cancer.*

The table shows the duration from time they were first diagnosed with cancer. The duration with the highest number was 7 - 12 months, which had 6 participants. This was followed by the duration of more than 12 months which had 4 participants and 1 - 6 months which had 3 participants. The least was less than one month which had 2 participants.

Chemotherapy	Radiation	Surgery	Chemo-Rad	Surgery-chemo	Surgery- radiation	All Three
1	1	0	4	3	1	5
Total: 1	1	0	4	3	1	5

Table 6: *Treatment modality.*

The table above shows treatment modalities and these include chemotherapy, radiation and surgery. The table shows that most participants received all three treatment modalities, while 4 received chemo and radiation; 3 surgery and chemo; 1 surgery and radiation and 1 received radiation only. None of the participants received surgery only as the only treatment modality.

Hypertension	Diabetes	COPD	RVD-R	Nil
4	1	1	4	5

Table 7: *Co-morbidities.*

The table above shows the co-morbidities that some of the participants had. Four of the participants presented with hypertension and another four where HIV positive while five had no co-morbidities. One had diabetes mellitus and the other had chronic obstructive disease.

Depressed	Denial	Anger	Worried but Hopeful
4	5	3	2

Table 8: *Feeling after being diagnosed with cancer.*

The participants presented with different feelings after being diagnosed with cancer. Five were in denial while four were depressed and three presented with anger. Only two from the total number of fifteen participants were worried but hopeful for a good outcome. Most of the participants were in denial upon being diagnosed with cancer and couldn't believe what they were hearing from the Doctors, followed by some who fell into depression upon hearing the sad news

Loss of self esteem	Happy and hopeful	Cancer pain	Depressed	Anger	Insomnia
3	3	2	4	2	1

Table 9: *Current feeling.*

The current feeling of the participant as follows; three were happy and hopeful while four were depressed; three had low self-esteem which was mostly due to the side effects of treatments. Only one patient presented with insomnia while two had cancer pain and the other two presented with anger management issues.

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Positive affect	Negative affect
6	9

Table 10: *PANAS scoring system.*

The PANAS scoring system of current mood of participants showed that most participants had a negative affect and only 6 from the total of 15 had a positive affect at the time. This was mostly attributed patients being scared to die from their cancers. Patients also reported reduced levels of self-esteem owing to effects of treatment such as hair loss, general body weaknesses, and medicine side effects such as nausea and vomiting.

This statistic signifies that cancer patients need psycho-therapy to be added to their standard treatment of cancer, to keep their mental heal well and to be able to pick up any mental health disorder that arises so it can be treated accordingly.

Discussion

The psychological well-being and emotional feeling of the participants during the period under research showed that most had a psychological problem owing to being diagnosed with cancer, of which most presented with depression, reduced self-esteem and denial. This was due to the fact that cancer was looked upon by most as death sentence as it is the third leading cause of death globally and was responsible for an estimated 9.6 million deaths worldwide in the year 2018 [13]. This was mostly due to late diagnosis as by the time patients came to the hospital the cancer has already progressed hence reducing the chances of survival.

The commonest psychological disorder they presented with was denial and depression. While 5 out of the total 15 participants presented with cancer pain, reduced self-esteem and anger. Only two from the total sample size were mostly happy and hopeful. This was owed to the fact that most did not have full information about the type of cancer they had and based the outcome of treatment on what they were feeling at the time and society beliefs about cancer. This as a result greatly affected their mood which led to most of them having psychological problems that most did not think were a problem at the time and considered it as a normal feeling. The was also seen in the PANAS scoring system which showed that a total of 6 had a positive affect while a total of 9 had a negative affect indicating that most had negative feeling at the time. The results found coincided with the research that was done by Anuk were he found that incidence of psychological disorders being diagnosed for the first time in patients with cancers was very high and was 30 - 60% [4].

The commonest disorder was depression. Most of the participants fell into depression after being diagnosed with cancer because they believed they now had a short time to live. Most were no longer looking forward to soon getting better but were instead feeling as though they are getting worse due to the effects of chemotherapy. This was mostly due to not having adequate information about the type of cancer they have and the side effects of the treatment they are receiving. As a result of depression this affected the recovery process as some were not eating properly nor were they taking good care of themselves.

Study Limitations

The study limitations worth noting were as follows. Firstly, there was no available empty rooms for subjects' confidentiality of our participants who were unable to read and write and needed a translator which may have made these subjects reluctant about opening up and expressing themselves fully.

Some subjects also claimed to have lack of basic knowledge concerning their disease or their treatment options and some were reluctant to provide their information event after they were assured that the purpose of this study is purely for academic purposes and that all their identity will be kept confidential.

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Conclusion

In conclusion, most of the patients that were newly diagnosed with cancer suffer from one or more psychological disorders with depression being the commonest. These negatively affect the disease progression as well as treatment outcome in the long run.

Recommendations

1. Education of people about cancer and treatment side effects.

2. Education of people about psychological problems and their signs and symptoms.

3. Cognitive behavioral therapy as part of standard care to all cancer patients.

Acknowledgement

Bibliography

1. American Cancer Society. "Cancer facts and figures" (2020).

2. Zambia National Cancer Control Strategic plan (2016).

3. J Zhu., *et al*. "First-onset mental disorders after cancer diagnosis and cancer-specific mortality". A nationwide cohort study". *Annals of Oncology* 28 (2017): 1964-1969.

4. Anuk., *et al*. "The characteristics and risk factors for common psychiatric disorders in patients with cancer seeking help for mental health". *BMC Psychiatry* (2019): 269.

5. Thombs BD., *et al*. "Rethinking recommendations for screening for depression in primary care". 184 (2011): 413-418.

6. Gregurek R., *et al*. "Psychological problems of patients with cancer". *Psychiatria Danubina* 22.2 (2010): 227-230.

7. World Health Organization. Cancer fact sheets (2018).

8. Prakash S., *et al*. "Assessment of spectrum of mental disorders in cancer patients". *The Journal of Cancer Research and Therapeutics* 14.6 (2018): 1312-1315.

9. Suija K., *et al*. "Patients' experience with cancer care". A qualitative study in family practice". *The European Journal of General Practice* (2012): 732568.

10. Almigbal TH., *et al*. "Assessment of psychological distress among cancer patients undergoing radiotherapy in Saudi Arabia". *Psychology Research and Behavior Management* (2019): 691-700.

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11. Sibulwa S., *et al*. Every part of me has changed"-Shared lived experiences of adolescents living with cancer in Zambia (2019).

12. Johanna E Maree and J Mulonda. "My experience has been a terrible one, something I could not run away from": Zambian women's experiences of advanced breast cancer". *International Journal of Africa Nursing Sciences* 3 (2015): 24-30.

13. World Health Organization. Cancer fact sheets (2018).