

RESEARCH ARTICLE

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Psychosocial Support and Cost Burden of Cancer Among Patients Attending Tertiary Oncology Clinics in Lagos State, Nigeria

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Abstract

Background: Cancer management brings about changes in patients' paths of life, in their daily activities, work, relationships, and family roles, and it is associated with a high level of patient psychological stress and financial toxicity. The objective of this study was to assess the psychosocial support and financial burden of cancer patients and determine socioeconomic factors that impact them. **Methodology and Methods:** This was a descriptive cross-sectional study among 240 cancer patients in Lagos University Teaching Hospital (LUTH) and Lagos State University Teaching Hospital (LASUTH) in Nigeria. The respondents were recruited consecutively and data was collected using structured, adapted, interviewer administered questionnaires. The data was analyzed using epi info software version 7.1 with chi-square used to test for associations and the level of significance was set at $p < 0.05$. **Results:** Overall, 74.6% of respondents had perceived psychosocial support scores higher than 50 out of 100. The family was the most common source of support across the emotional, financial and tangible support dimension's (91.7%, 83.8% and 85.4%) while healthcare professionals (60%) were the commonest for informational support. Overall, 69.6% had COST scores less than 50% indicating worse financial toxicity. Statistical associations were found between cost burden and cancer type ($p = 0.01$), age ($p < 0.0001$) and financial support ($p < 0.0001$). Older patients, those who had financial support, and those with gynecological cancers had a decreased financial burden. For psychosocial support associations were seen with employment status ($p = 0.02$), and treatment ($p < 0.0001$). Higher psychosocial support for patients who were employed and had begun treatment. **Conclusion:** The majority of respondents experienced high levels of financial toxicity but adequate psychosocial support. More research is needed, as well as the inclusion of support groups into clinics and the availability of loans to help with the initial costs.

Keywords: Cancer- psychosocial support- cost burden- Out-of-Pocket expenses (OOPE)- Nigeria

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Introduction

Cancer is rapidly becoming a public health crisis in low and middle-income countries (Jedy-Agba et al., 2012). In Nigeria, some 100,000 new cancer cases occur every year, with a high case-fatality ratio. In 2020 about 11% of the estimated 1,109,209 new cases of cancer and 711,429 cancer deaths in Africa were from Nigeria (Sharma et al., 2022).

In sub-Saharan Africa, patients often present with advanced disease and face other obstacles such as the cost of oncological care, poor infrastructure, and the scarcity of skilled health-care workers (Kingham et al., 2013). The cost of treatment of cancers is generally very high, making care very difficult in the developing nations. The average

cost of Care for Cancer of the cervix in Zaria, Northern Nigeria is estimated at \$1500 (Oguntayo et al., 2013). In view of the economic facts and figures concerning our economic status and health, it is almost impossible for an average person to offset his/her health bill regarding cancer (Oguntayo et al., 2013).

In Nigeria, the burden of care rests largely on relatives (Ohaeri et al., 1999). A cancer diagnosis is a major event for the person diagnosed and also to their family and caregivers. Some studies report that a cancer diagnosis actually has a greater impact on family members than patients (Girgis et al., 2019). Social support is an important component of cancer care as it is associated with fewer psychological symptoms and greater well-being and appears to be a protective factor against negative health

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outcomes, including mortality (Applebaum et al., 2015).

In 2018, cancer was estimated to have cost society 199 billion dollars in Europe. The total cost of care must be documented in order to demonstrate value for money and the possibility for better patient outcomes through cost-effective expenditure (Hofmarcher et al., 2020).

Medical care spending on cancer has increased dramatically in recent years as a result, the cost of care per patient has grown substantially (Davidoff et al., 2013). There is a growing concern that the potential out-of-pocket (OOP) cost may discourage treatment, and creates substantial financial hardships for cancer patients and their families (Davidoff et al., 2013). Families may also be at risk of financial distress due to lost wages and other treatment-related expenses (de Souza and Wong, 2014). Cancer may exacerbate financial stress, thereby influencing their livelihood, their ability to maintain employment benefits including health insurance, manage financial obligations, and participate meaningfully in cancer treatment (Callahan and Brintzenhofesoc, 2015).

The amount of psychosocial support patient receives from family, friends and healthcare providers has considerable effect on health outcomes and adaptive strategies to cancer therapy. In a low and middle-income country like Nigeria the cost burden is especially crucial as cancer therapy is financially demanding.

This study aimed to assess the psychosocial support patients diagnosed with cancer received and estimate the cost burden of their care. Previous research has focused on cancer prevalence, quality of life, and outcomes; however, more research is needed to measure and characterize cost burden and the support patients receive, as well as to understand how it affects their quality of life. In addition, healthcare providers need to be trained to counsel patients and their families so they can make patient-centered treatment decisions that reflect their preferences and values.

Materials and Methods

This descriptive cross-sectional study was carried out among patients 18 years and above diagnosed with cancer at least a month before and treated in two tertiary oncology clinics in Lagos, Nigeria. The two tertiary hospitals in Lagos that were used in this study; Lagos University Teaching Hospital (LUTH) and Lagos State University Teaching Hospital (LASUTH). The minimum sample size of 227 was calculated using the Cochrane formula at 95% confidence interval with a prevalence of 18.1% in a Yale University study (Fenn et al., 2014).

Methodology

Ethical approval was obtained from the Health Research and Ethics committee of Lagos University Teaching Hospital. Written informed consent was obtained from each respondent before administering the questionnaire. The nature of the study was adequately communicated to the participants and their right to withdraw from the study at any point in time was voluntary. The participants were assured of confidentiality, as their names were not required for the study. A consecutive sampling method

was used to select participants for the study. LUTH had two oncology clinics, a private clinic from Mondays to Fridays and a general clinic on Tuesdays and Thursdays. On the other hand, the LASUTH oncology clinic runs on Tuesdays and Fridays. Research assistants collected data in each clinic simultaneously and patients who met the inclusion criteria and had given informed consent were recruited consecutively for the study until the sample size was reached.

Inclusion criteria

1. All patients diagnosed with various cancers undergoing treatment.
2. Patient who have been diagnosed at least one month prior.

Data Collection Tools and Techniques

An adapted structured, interviewer-administered questionnaire was administered to collect data for the study. It was developed from pre-existing studies and standard tools: Medical Outcomes Study (MOS) Social Support Survey Instrument, predicting psychological distress of informal carers of individuals with major depression or bipolar disorder, The Caregiver Indirect and Informal Care Cost Assessment Questionnaire, the Comprehensive Score for Financial Toxicity (COST) and Economic Burden and Quality of Life of Primary Caregivers of Lymphoma patients attending the Paediatric Cancer Unit at Komfo Anokye Teaching Hospital (Sherbourne and Stewart, 1991; de Souza et al., 2017; Dawson, 2018; Landfeldt et al., 2019).

The questionnaire comprised three parts: sections A-C

Section A

Questions regarding the socio-demographic characteristics of the respondents.

Section B

Questions that assessed the psychosocial support received by the patients.

Section C

Questions that determined the cost burden of cancer treatment on the patients.

The questionnaire was pretested on 25 patients attending clinics in Lakeshore Cancer Centre Victoria Island, Lagos. This was to ensure comprehension by the intended population and the result was used to restructure the questionnaire.

Scoring method

Psychosocial support was assessed under four classifications: Emotional/Informational support, Tangible Support, Affectionate Support and Financial Support. Each item under each category was in a 4-point Likert scale and scored as: none of the time -1, some of the time -2, most of the time -3, all of the time -4. As a result, the range of values was 12-48, with higher scores indicating better psychosocial support. The score for each respondent was then converted to a 0-100 scale (Sherbourne and Stewart, 1991). To examine what socioeconomic characteristics

impact psychological support, scores of over 50 out of 100 were rated as higher scores, while those with scores of less than 50 out of 100 were rated as lower scores.

The direct cost was classified as direct medical and non-medical cost, with the categories labelled “A-D” representing direct medical cost and category “E” representing direct non-medical cost. The total direct cost was calculated by adding the total medical and non-medical costs.

Indirect cost was calculated by estimating the loss of work hours for the patient that is working. Loss of work hours was quantified as “missed entire days”, “Closed 2 hours earlier”, “Closed 4 hours earlier”, and “Closed 6 hours earlier”. For the patient that was not working, the indirect cost was calculated as job loss (Dawson, 2018; Landfeldt et al., 2019).

Ten statements assessing the cost burden of cancer treatment on the patient were scored on a 4-point Likert scale and graded into Strongly Agree-4 marks; Agree-3 marks; Disagree-2marks; Strongly Disagree-1mark (the scoring was reversed for 6 of those ten items). The lower the score, the worse the financial toxicity (de Souza et al., 2017). To examine what socioeconomic characteristics impact financial burden, scores of <50% were rated as significant financial burden and score of > 50% or more

Data Analysis

Data collected from fully completed questionnaires were analysed using the statistical software Epi Info 7. Results were represented in frequency Tables. The Chi-square test was used to test for association between variables. The level of significance (p) was set at (< 0.05).

Results

Sociodemographic Characteristics

The respondents age ranged from 18 to 87 years with the mean age being 56.9 ± 13.9 . Most respondents were female 66.7% (n=160), married (78%, n=188), had completed at least primary level of education (97.5%, n=234) and were employed or self-employed (64.2%, n=154). Of the 131 patients that gave data on their monthly income, 24.4% earned N30,001-N60,000 monthly and the mean income was N105,416.6. Additional characteristics are shown in Table 1.

Psychosocial Support scores and Sources

Of the 240 respondents, affectionate support was the highest perceived form of support with mean score of 67.1 out of a 100. The least perceived form of support was financial support, with respondents having a mean score of 56.3 out of a 100. Across all the four dimensions the respondents perceived social support was high. The mean social support as seen in Table 2 was 61.7 out of 100.

As shown in Table 3, Family was the most common source of emotional support with 91.7% of respondents selecting it as a source of support. Friends were the second commonest source of support in this dimension, with 29.2% of respondents selecting it. However, 60% of the respondents said doctor/nurse as their source of informational support.

Table 1. Sociodemographic Characteristics of Patients with Cancer Attending Tertiary Oncology Clinics in Lagos, Nigeria.

Characteristics	Frequency (n=240)	Percentage (%)
Age (years)		
18-21	5	2
21-40	21	8.8
41-60	117	48.8
>60	97	40.4
Mean \pm SD = 56.9 ± 13.9		
Sex		
Male	80	33.3
Female	160	66.7
Marital Status		
Single	20	8.3
Married	188	78.3
Divorced	6	2.5
Separated	3	1.3
Widowed	23	9.6
Level of Education Completed		
No formal education	6	2.5
Primary	27	11.3
Secondary	79	32.9
Post-secondary	128	53.3
Employment Status		
Unemployed	36	15
Employed	76	31.7
Self-employed	78	32.5
Retired	50	20.8
Estimated Monthly Income (n=131)		
\leq N30,000	31	23.7
N30,001-N60,000	32	24.4
N60,001-N90,000	13	9.9
N90,001-N120,000	26	19.9
>N120,000	29	22.1
Mean =N105,416.6		

Direct and Indirect Cost

All (100%) respondents had OOPE, only 67 respondents stated their estimated expenditure and out of that, 55.2% had expenditure greater than N900,000, and 22.4% had estimated expenditure lower than N300,000.

Table 2. Mean Psychosocial Support Scores of Patients with Cancer Attending Tertiary Oncology Clinics in Lagos, Nigeria.

Item	Mean Score (SD)
Emotional/informational support	58.5 (24.4)
Tangible support	62.7 (28.9)
Affectionate support	67.1 (25.1)
Financial support	56.3 (31.8)
Mean social support total	61.7 (22.5)

Table 3. Sources of Support of Patients with Cancer Attending Tertiary Oncology Clinics in Lagos, Nigeria.

Characteristics	Frequency	Percentage (%)
Emotional support		
No one	11	4.6
Family	220	91.7
Friends	70	29.2
Work associates	13	5.4
Religious group	35	14.6
Doctor/Nurse	6	2.5
Informational support		
No one	33	13.8
Family	76	31.7
Friends	34	14.2
Work associates	9	3.8
Religious group	16	6.7
Doctor/Nurse	144	60
Others	7	2.9
Financial support		
No one	30	12.5
Family	201	83.8
Friends	49	20.4
Work associates	2	0.8
Religious group	17	7.1
Doctor/Nurse	1	0.4
Tangible support		
No one	18	7.5
Family	205	85.4
Friends	45	18.8
Work associates	3	1.3
Religious group	6	2.5
Doctor/Nurse	2	0.8

(*Multiple responses allowed)

The mean estimated expenditure was N1,638,059. About a fifth (22.9%) of respondents lost their jobs during treatment and alternative financing was mostly from relatives (61.7%), and only 2.9% had health insurance of any form. More details are shown in Table 4.

Associations

As detailed in Table 5, Statistical associations were found between cost burden and cancer type (p=0.01), age (p<0.0001) and financial support (p<0.0001). For psychosocial support associations were seen with employment status (p=0.02), and treatment (p<0.0001).

Discussion

The age of the respondents ranged from 18 to 87 years, there were 117 respondents aged 41-60, the highest of all age groups and the mean age of the respondents was 56.9 ± 13.9. About two-thirds of respondents were employed or self-employed, less than a quarter were unemployed and about a fifth were retired. This was

Table 4. Direct and Indirect Cost of Treatment of Patients with Cancer Attending Tertiary Oncology Clinics in Lagos, Nigeria.

Item	Frequency (n=240)	Percentage (%)
Direct Cost		
Out-Of-Pocket Expenses*		
Drugs/Medicines	216	90
Consultation	182	75.8
Laboratory Test	220	91.7
Hospital Admission	150	62.5
Travel/transportation to seek care	193	80.4
Other	20	8.3
Total estimated expenditure**		
≤N300,000	15	22.4
N300,001-N600,000	10	14.9
N600,001-N900,000	5	7.5
>N900,000	37	55.2
Other Sources of Financing*		
Contribution from relatives	148	61.7
Health insurance	7	2.9
Donations/gift	52	21.7
Borrowed money	29	12.1
Indirect Cost		
Reduced time at work		
Lost job due to condition	55	22.9
Missed multiple days	113	69.8
Time spent at the hospital		
4-6 hours	106	44.2
7-10 hours	85	35.4

(*Multiple responses allowed); (**Estimated expenditure could only be obtained from 67 patients)

comparable to a study performed at the University of Port Harcourt Teaching Hospital (UPTH), where the patient age ranged from 18 to 80 years and where the majority of respondents were employed, about a quarter were unemployed and a few patients retired (Korubo et al., 2018). It was also equivalent to a study at The University of Chicago Medicine and The NorthShore University Health System whose mean age was 58.426 ± 11.47 (de Souza et al., 2017).

About a quarter of the 131 patients who gave data on their monthly income earned monthly below N30,000 (~72USD), less than a quarter earned monthly > N120,000 (~290USD), and the mean income was N105,416.6 (~253USD). This differed from a study at University College Hospital Ibadan Nigeria, where only 56 (25%) out of 188 income earners, estimated monthly income above 12,500 Nigerian Naira (~ 100 USD at the time). The majority, 132 (60%) earned monthly income below the above value. The difference can be attributed to the naira dropping to the dollar over the years and the respondents being only among women with breast cancer in Ibadan Oyo State, a less industrialized and less populous state

Table 5. Factors Associated with Cost Burden and Psychosocial Support of Patients with Cancer Attending Tertiary Oncology Clinics in Lagos, Nigeria

Cost Burden	Significant (n=167)	Non-significant (n=73)	x ²	p-value
Age (years)				0.00*
18-21	2 (40.0)	3 (60.0)		
21-40	20 (95.2)	1 (4.8)		
41-60	91 (77.8)	26 (22.2)		
>60	54 (55.7)	43 (44.3)		
Cancer Being Treated			16.21	0.01
Breast	88 (77.9)	25 (22.1)		
Gastrointestinal	27 (65.9)	14 (34.1)		
Gynecological	10 (40.0)	15 (60.0)		
Lung	4 (57.1)	3 (42.9)		
Lymphoma	3 (100.0)	0 (00.0)		
Prostate	16 (66.7)	8 (33.3)		
Others	19 (70.4)	8 (29.6)		
Financial support			15.26	0.00
Good	88 (60.3)	58 (39.7)		
Poor	79 (84.0)	15 (16.0)		
Psychosocial Support				
	Higher (n=179)	Lower (n=61)	x ²	p-value
Treatment Received			9.91	0.00
Yes	163 (78.0)	46 (22.0)		
No	16 (51.6)	15 (48.4)		
Employment Status			10.21	0.02
Unemployed	21 (58.3)	15 (41.7)		
Employed	58 (76.3)	18 (23.7)		
Self-employed	56 (71.8)	22 (28.2)		
Retired	44 (88.0)	6 (12.0)		

*Fisher's Exact

than Lagos (Ntekim et al., 2009).

Neither the respondents' employment status nor monthly income had a direct influence on cost burden; however, employment status was strongly associated with higher psychosocial support and those with higher financial support on the other hand, had a reduced financial burden. This might indicate that socioeconomic factors indirectly impact the financial burden, as people who are employed are more likely to have better financial support.

The most common cancer was breast cancer and the majority of patients were diagnosed within the last five years. The majority of patients had received chemotherapy and almost half had undergone surgeries as treatment. The study also found that treatment had a strong correlation with good psychosocial support, showing most of the respondents with any form of treatment had better perceived support from healthcare professionals, fellow cancer patients, family and friends. This differed from a study at Duke University Medical Centre where although the most common cancer was breast cancer all respondents had received chemotherapy and 10% had undergone surgery. The difference is attributed to the inclusion criteria of the study being patients actively receiving chemotherapy or hormonal therapy and the study being in a high-income country with an earlier presentation and

treatment commencement time (Zafar et al., 2013).

Mean social support was 61.7 out of 100, with respondents reporting higher affectionate support (mean score = 67.1) than tangible (mean score = 62.7) or emotional support (mean score = 58.5). This was similar to a study in Greece where overall social support was 68 out of 100, with mothers reporting higher affectionate support (mean score = 70) than tangible (mean score = 66) or emotional support (mean score = 67) (Nicolaou et al., 2015). These scores were, however, lower than those found in a 2016 study of women who had undergone chemotherapy (Jatoi et al., 2016). This gap might be because all patients had received treatment, which this study found to be linked to high psychosocial support.

Respondents' families were the most common source of support across the dimensions. Across the dimensions of emotional, financial and tangible support, friends were the second commonest source of support after families. However, in informational support, most of the respondents selected a doctor/nurse as a source of support, followed by family and friends of respondents. This was similar to a Bulgarian study in which partners were considered the most supportive followed closely by children and parents. Partners were considered as the most common source of emotional support. Health care

professionals were considered as the most common source of informational support (Velikova-tzonkova, 2013). This was also similar to an Ethiopian study in which perceived social support was low from the “friends” sub-dimension, to which the participants reported moderate support (mean score = 15.86 ± 9.44). Perceived support was high from family (mean score = 25.52 ± 4.97) (Wondimagegnehu et al., 2019). This result may indicate that the cancer burden has a cumulative effect on cancer patients’ families and friends, as well as that most patients depend on healthcare professionals for informational support, which could have a positive impact on adjustment, mental state, and well-being, as numerous studies have suggested (Usta, 2012; Applebaum et al., 2015).

In a Duke study conducted over two years, the financial burden reported was 42% and 47% compared to the higher financial burden (69.6%) reported in this study. One hundred and sixty-eight (168) patients completed the financial burden question: 81 (48%) reported high financial burden (Zafar et al., 2013; Chino et al., 2014). It was similar to a Nigerian study where most respondents (82%) perceived the economic burden to be significant (Mustapha et al., 2015). This difference could be attributed to the study taking place in a LMIC where there is less earning power, little to no subsidized health care packages and only 2% having any form of health insurance. Thereby making patients surprised at the amount of OPE, financial stress and dissatisfaction we generally see in this study.

Those under 60 years were more likely to have a higher financial burden. Thus, younger age was significantly associated with the cost burden. This demographic profile mirrored those of other research in which being younger was associated with greater financial toxicity (Shankaran et al., 2012; Yousuf Zafar et al., 2015; Knight et al., 2018). This may be due to older people having more family including children, grandchildren also possibly having more friends from relationships over their lifetime and having been employed or already retired which were factors that had links to the less significant cost burden.

There was also a correlation between cancer type and cost burden. Respondents with certain cancer types (breast, gastrointestinal, others) had a higher proportion with high financial burden as such, those cancer types were associated with a high financial burden. While those with gynaecological had a lower percentage with increased financial burden. In Ibadan where colorectal cancer patients had the highest cost burden, the difference may be due to the low number of colorectal cancer patients found in this study and breast cancer having the largest number of respondents (Mustapha et al., 2015).

This study showed that family and friends provided the majority of psychosocial support to cancer patients, and the majority of them considered it to be substantial. It also revealed that high financial toxicity is common among cancer patients in a low-middle-income country like Nigeria, where most patients pay for treatment out of pocket and only a handful have insurance coverage. Older patients tended to have better financial support and lower cost burden and approximately a quarter of respondents lost their jobs during treatment. There was

a mean estimated expenditure of 1.6M naira (\$4200) in the 67 respondents who disclosed their expenditure. This emphasizes the need for health insurance implementation in low- and middle-income countries, as well as developing innovative ways to fund parts of treatment and integrating support groups to aid patients who lack support systems.

Author Contribution Statement

All authors contributed equally in this study.

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None.

Approval

Ethical approval was obtained from the Health Research and Ethics committee (HREC) (ADM/DCST/HREC/APP/549) of Lagos University Teaching Hospital. Written informed consent was obtained from each respondent before administering the questionnaire. The nature of the study was adequately communicated to the participants and their right to withdraw from the study at any point in time was made voluntary. The participants were assured of confidentiality, as their names were not be required for the study.

Ethical Declaration

We declare compliance with ethical standards

Data Availability

Available upon demand

Conflict of interest

All authors declare no conflict of interest

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