Cancer Patients' Perceived Need for Information and Education on Sexuality Challenges in a Regional Oncology Center in South-Eastern Nigeria

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Summary

BACKGROUND

Cancer patients in low and middle-income countries (LMIC) experience sexuality concerns most often un-disclosed by patients and unaddressed by oncologists. This study investigated adult cancer patients' need for information and education on perceived sexuality challenges in Nigeria.

MATERIAL AND METHODS

This descriptive, cross-sectional study enlisted 298 adult cancer survivors. A pre-tested researcher-developed questionnaire was used for data collection and analysis done with IBM SPSS, version 19.0 using descriptive and inferential statistics (at $p<0.05$).

RESULTS

Findings showed that only 5.4% have tried discussing sexuality concerns with caregivers, (282=94.6%) had never even when the majority felt anxious about the sickness (3.66±1.12) and depressed about the loss of a body part (3.13±1.41); females had difficulties performing roles as mothers/wives (3.45±1.47), men reported having difficulties performing roles as fathers/husbands (3.53±1.52). The majority considered discussions on sexuality as important (4.17±1.36) and desired to a very high extent discussion/information on the impact of cancer and cancer treatment on sexuality and sexual life/behaviour (4.36±0.88) with nurses (67.1%) than doctors.

CONCLUSION

Cancer patients need information on cancer and sexuality. Health care providers should include such discussions during patient assessment and treatment. Sexuality discuss, although appreciated is a sensitive issue that requires skills and ongoing training for cancer care professionals.

Keywords: *Cancer Patients, Education, Information, Sexuality, Sexuality Challenges.*

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Introduction

Preservation of sexual function is a component of quality of life, yet it remains one of the unmet needs among cancer survivors (1, 2). Sexual functioning is a value-based patient-centred outcome for breast cancer patients (3, 4) and cancer or the treatment can negatively affect sexuality and intimacy; hinder the ability to engage in sexual activities leading to decreased quality of life of patients with cancer (5, 6). Depression, anxiety, loss of self-esteem, grief

and loss of body part, disturbances in body image and physical unattractiveness may impact sexual health and wellbeing negatively (1, 7). Health care professionals may focus attention on the treatment of cancer and overlook the sexual problems associated with cancer and its treatment (8). Most cancer patients (80.4%) and partners (73.7%) did not receive any information regarding sexuality (4) yet most patients valued an opportunity to discuss sexuality but had unmet needs associated with health system and health information (9, 10).

Cancer treatment can influence fertility in both men and women while chemotherapy can cause direct toxicity to the ovaries leading to either temporary amenorrhea or early menopause. (11). Studies showed that up to 85% of women with breast cancer experience physical sexual problems and reduced desire due to treatment-induced menopause (13, 14). Radiation treatment of the genital area can cause pain during ejaculation for men, decrease the amount of seminal fluid and cause a breakdown of skin integrity while the inability to achieve an erection can give feelings of sexual inadequacy (11, 14, 15).

Information and support about intimacy and sexuality can reduce the struggle encountered by cancer patients and their partners (16). Despite the growing awareness of the importance of such information, oncologists do not routinely provide information on sexuality to their patients (17, 18, 14). Oncologists should pay attention to patients' sexuality concerns since patient–partner relationship in an affectionate intimate relationship enhances better (psychosocial) outcomes and adaptation to disease (20, 21).

Preferences may differ from patient to patient on who should initiate the discussion on sexuality issues. In a culture where everything about sex and sexuality is shrouded in secrecy, it can be very difficult for patients to initiate such a discussion. Literature showed that some patients want to talk about it, and others desired that the providers initiate the discussion (11) however, patients preferred nurse practitioners to provide information about sexuality supported by a brochure or website when treatment is ongoing (4, 22). Sexuality assessment is part of holistic care and healthcare providers need to help patients open up about sexuality challenges.

According to the American Cancer Society (23), after finishing cancer treatment people may have prolonged life-long problems with sexuality which might affect relationships therefore cancer patients are encouraged to continue reporting problems related to sexuality

In Nigeria, religion and cultural factors play major roles in people's disposition towards talking about sex. Discussions about sexuality are concealed in secrecy and handled as a private matter (24). African nurses (25) reported culture, stigma and discrimination as barriers to discussing sexual health with cancer patients and a similar finding was noted in India (19). Sex is believed to be primarily for the procreation and pleasure of men, therefore in such a cultural context; men may not pay attention to the feelings of women (26). Studies outside Nigeria conversely reported that patients preferred an open discussion about sexuality with a health care provider where the provider-initiated sexuality and sexuality-related issues during a conversation (26, 27, 14). In clinical practice in the study centre, there seem to be no discussions and no published literature on the effects of cancer and treatment on sexuality. Sexuality seems a taboo subject among patients, despite educational level. Male patients with erectile dysfunction were observed speaking harshly and aggressively to their wives whom they suspect of sexual infidelity. Such accumulated anger and resentment can destroy closeness between partners. The questions that underpinned this study were: do cancer patients in Nigeria have

sexuality concerns? Who should initiate the discussion about sexuality and how important is information about sexuality to cancer patients? The study, therefore, determined the extent of respondents' perceived need/desire for information and education on sexuality and cancer; respondents' preferred choice of whom to discuss cancer and sexuality issues with and who should initiate the discussion and perceived sexual relationship challenges resulting from cancer therapy that informed respondents' desire/need for education and information.

Materials and Methods

Design/Study Setting

The descriptive survey design was used for the study. University of Nigeria Teaching Hospital Enugu was the setting for the study. The health facility offers medical, surgical and radiological services for the management of cancer with a high volume of patients. The centre is a referral centre for all cancer patients within the geopolitical zone and beyond.

Sampling

Using power analysis, 298 cancer patients receiving treatment or on follow-up visits at the oncology clinics of the hospital were recruited using the purposive sampling technique with inclusion criteria.

Respondents included were 20 years and above, histologically diagnosed with cancer, diagnosis disclosed to the patient and should be receiving/received treatment, must be in the clinics, willing to participate and were not in pain or very ill during the study period.

Data Collection

The instrument for data collection was a validated pre-tested interviewer-administered questionnaire. The questions were adapted from the Sexual Adjustment Questionnaire (SAQ) by Waterhouse and Metcalf (29) and the Marital Satisfaction scale (MSQ) by Osinowo and Oyefeso (30). The SAQ consists of 35 items and is measured on a 5 point Likert Scale ranging from Not at all (1) to Very much (5). SAQ was developed specifically for application in studies of cancer patients and survivors and includes items focused on the separate dimensions of sexuality and sexual function and the effects of illness on respondents' sexual relationships. The Marital Satisfaction Questionnaire was used to assess relationship satisfaction between patients and their spouses and consists of 15 items that were assigned to measure three subscales (tension, emotion and attitude) regarding the degree of satisfaction with one's partner. It is measured on a 5 point Likert scoring scale ranging from dissatisfied to very satisfied.

The SAQ and MSQ were adapted for the present study with further additions to encompass the respondent's sexuality information needs thereby giving a total of 26 items and four sections: Sections A and B comprise 11 questions on demographic and medical data; Section C had 7questions that got information on the cancer patients' need for sexuality information and education while Section D consists of 8 items determining the relationship challenges of cancer survivors.

Face and content validity of the questionnaire was done by three experts (a professor of nursing, a consultant surgeon at the study centre and a senior practising palliative care nurse)

The reliability test was done with twenty-nine (29) copies of the questionnaire administered once to hospitalized cancer patients who were excluded from the study using the split-half method. Responses were analyzed using Cronbach's Alpha value of 0.81.

Three trained research assistants (nurses working in the centre) helped with data collection at each clinic day. Four contacts in a week were made at the oncology clinic and patients were interviewed once. In each contact, data collection was completed before the routine

clinic activities to reduce patients being distracted. New respondents that met the inclusion criteria were included. The data collection lasted for eight (8) weeks (March to April 2016) when the calculated sample size was reached. The return rate was 100% as it was an interviewer-administered questionnaire.

Ethical considerations

Ethical approval was obtained from the ethics committee of the study centre (NHREC/05/2016B-FWA00002458-IRB00002323). Informed consent was obtained from respondents. Confidentiality and anonymity were guaranteed. Administrative permits were obtained from appropriate authorities.

Data Analysis

Data were analyzed using the Statistical Package for Social sciences (SPSS) Version 19.0. Descriptive statistics using frequency proportions, percentages, mean and standard deviations were done. Scaled items were assigned numerical scores to yield a mean score for each variable as follows: Always: 5points, almost always: 4points, sometimes: 3points, Few times: 2points, and never: 1 point. The mean value of 3 was considered as the mean decision point. Any item that scores ≥3 was considered significant, while any item with the mean value <3 was regarded as not significant.

Table 1:
Respondents' Demographic Data

Variable	Frequency	Percentage %
Age		
20-39 years	28	9.3
40-59 years	154	51.7
60-79 years	103	34.6
80 years and above	13	4.4
Gender		
Male	97	32.6
Female	201	67.4
Marital status		
Married	207	70.1
Single	70	20.3
Widowed	16	6.3
Divorced	4	3.3
Education		
No formal	29	9.7
Primary	46	15.4
Secondary	105	35.2
Tertiary	118	39.7
Employment status		
Employed	30	10.1
Self-employed	115	38.6
Retired/working	85	28.5
Students/ apprentice	24	8.1
Unemployed	44	14.7
Have you tried discussing sexuality concerns with your caregivers?		
Yes	16	5.4
No	282	94.6

Results

The majority 201 (67.4%) were females, 51.7% were in the predominant age group of 40-59 years, 223 (75.1%) were married, 29(9.7%) had no formal education, 46(15.4%) had primary education while 118 (39.6%) had tertiary education and 115 (38.6%) were predominantly self-employed (table 1).

Most 121 (63.4%) of the female respondents were in the pre-menopausal stage. The majority 196 (62.2%) had undergone combined treatment, surgery and chemotherapy and 176 (59.1%) had no co-morbidity, while hypertension, diabetes, cardiovascular disease and HIV/AIDS were the reported co-morbidities (13.4%, 8.4%, 8.4% and 8.7%) respectively. Most of the respondents had breast cancer 169 (56.7%) and prostate cancer 64 (21.5%) (Table 2).

Table 2:
Respondents' Medical Data

Variable	Frequency	Percentage %
Menopausal status for women		
Premenopausal	121	63.4
Postmenopausal	70	36.6
Number of treatments received		
Single	141	47.3
Double	96	32.2
Triple	61	20.5
Treatment types		
Chemotherapy	40	13.4
Surgery	3	1.0
Radiotherapy	16	5.4
Immunotherapy	82	27.5
Surgery /Chemotherapy	96	32.2
Surgery/Chemotherapy/ Radiotherapy	61	20.5
Presence of Co-morbidity		
Hypertension	40	13.4
Diabetes	25	8.4
Cardiovascular disease	25	8.4
HIV/AID	26	8.7
Stroke	6	2.0
Nil	176	59.1
Cancer stage		
Stage 1	13	4.4
Stage 2	31	10.4
Stage 3	124	41.6
Stage 4	130	43.6
Cancer type		56.7
Breast (females)	169	
Cervix (females)	9	3.0
Ovary (females)	14	4.7
Leukaemia (females)	3	1.0
Maxillofacial	5	1.7
Colorectal	13	4.4
Prostate (males)	64	21.5
Heamatological cancer (males)	21	7.0

Table 3 showed that 171(57.4%) desired to a very high extent discussion and information on the impact of cancer and treatment on sexuality and sexual life/behaviour (4.36±0.88), and 198 (66.4%) considered discussions on sexuality as important (4.17±1.36) while 130 (44%) desired to a very high extent informational materials on sexuality (3.50±1.55). None of the respondents discussed fertility concerns before or after treatment with their care providers. The majority 200 (67.1%) preferred to discuss their sexuality concerns with nurses followed by doctors while 245 (82.2%) were of the view that the patient ought to bring up the discussion, however majority 282 (94.6%) have never discussed sexuality concerns with their caregivers (Table 4).

Table 3:
The extent of respondents' perceived need/desire for information and education on sexuality and cancer

Variable	Very High Extent	High Extent	Moderate Extent	Low Extent	No Extent	M±SD
The extent to which discussion on the impact of cancer and cancer treatment on sexuality and sexual life/behaviour is desired	171	79	32	16	0	*4.36±0.88
The extent to which discussion on sexuality is considered important	198	31	20	20	29	*4.17±1.36
The extent to which some information materials on sexuality are desired	130	29	45	47	47	*3.50±1.55
The extent to which discussion on fertility concerns with care providers before or after treatment was undergone	0	0	0	0	298	1.00±0.00

Items with mean scores of ≥ 3 identified with (*) were considered significant information needs of the patient

Table 4:
Preferred Person to Discuss Sexuality Issues With

Preferred person	Frequency	Percentage %
Whom do you feel comfortable discussing cancer and sexuality issues?		
Nurse	200	67.1
Doctor	73	24.5
Other healthcare givers	25	8.4
Who do you think should initiate the discussion about cancer and sexuality?		
Patient	245	82.2
Doctor	41	13.8
Nurse	0	0.0
Anyone - patient or health care provider	12	4.0

Table 5 showed that the majority felt depressed about the loss of a body part (3.13±1.41); were anxious about the sickness (3.66±1.12); females had difficulties performing roles as mothers, wives and housewives (3.45±1.47) while males had difficulties performing roles as fathers, husbands and breadwinners (3.53±1.52).

Discussion

The mean age in this study was 50.45, 51.7% were in the age group of 40-59 years, and the majority were females 201 (67.4%) with 56.7% having breast cancer. Breast cancer and cervical cancer are the most frequently diagnosed cancers in females in sub-Saharan Africa (31) and (32) stated that females in Africa have a much higher risk of developing and dying from cancer than males. This could be attributed to risk factors common in women like reproductive behaviours, infections, dietary patterns and obesity (33). Seeing more females in the study could also be that females report illness more than males thereby utilizing health facilities more than males.

In this study, most patients reported at stages 3 (41.6%) and 4(43.6%). This could be due to delays in seeking health care services in the study environment due to financial difficulties, family conflicts and cultural influences. This agrees with (34) who reported that cancer patients in Nigeria present at late stages of illness due to multifaceted factors which call for awareness creation.

Table 5:
Perceived Sexual Relationship Challenges of Cancer Patients resulting from cancer therapy that informed the need for education and information

Variable	Always (5)	Almost always (4)	Sometimes (3)	Few times (2)	Never (1)	M±SD
Do you think it's your fault for coming down with this sickness	40	10	64	50	134	2.23±1.40
Do you feel depressed about the loss of your body part	56	91	47	45	59	*3.13±1.41
Have you difficulty performing your role as a mother, wife and a housewife	57	12	17	42	11	*3.45±1.47
Have you had any difficulty performing your role as a father, husband and breadwinner?	25	8	11	6	10	*3.53±1.52
Have you had any difficulty performing your role as a child to a parent?	16	24	1	93	162	1.78±1.15
Has your partner been avoiding you since this sickness	22	16	41	77	142	1.99±1.22
Have you been anxious about this sickness?	69	131	36	51	11	*3.66±1.12
Do you feel hopeless about this condition?	12	8	8	65	205	1.66±1.22

*Items with mean scores of ≥ 3 identified with (*) were considered significant relationship challenges to the patient

Cancer patients in this study desired to a very high extent to receive information and education on the effect of cancer and treatment on sexuality and considered the discussion to be very important. The majority indicated that they had not received such information from their providers. It could be because health care providers are always battling with excess workload and had no time for such discussions. The Health system in Nigeria is plagued with a shortage of healthcare providers making the available few to battle with excess workload (35, 36). Most patients in (2) wished to discuss sexuality health, but they felt health care providers do not provide an opportunity to talk about sexual issues or were ignoring their sexual needs. It could also be that the providers lack communication skills to discuss such private issues yet patients trusted information and materials from a health worker. Respondents in (15) lamented that they couldn't establish a relationship with an oncologist with whom to share sexuality challenges due to rushed consultations and busy staff while (19) noted that oncologists perceived that newly diagnosed patients may be overwhelmed with a cancer diagnosis and grappling to make decisions on treatment, may not be in an appropriate state of mind to discuss sexual health.

Sexuality and cancer were not routinely discussed by health care providers and respondents reported dissatisfaction with the information received (13, 37). Sexual dysfunction was never mentioned as a side effect of cancer in (15, 38) while (39) reported that 30.7% of young breast cancer survivors in Japan had unmet information needs and were dissatisfied with overall communication with medical professionals. Oncologists, therefore, need effective communication skills regarding sexuality issues.

Oral and written information through a brochure or via a website was desired by patients and partners in (40, 41, 37) while (6) noted that 48.6%, 35.3% and 27.2% respectively desired information about sexuality and direct conversation with a health care professional.

A majority, (67.1%) preferred to discuss the impact of cancer and its treatment on sexuality with nurses. This could be because nurses are closer to the patients and present in the wards round the clock. Nurses do feel responsible for initiating sexuality discussions (22, 10) but are hindered by lack of time and training, fear of causing patients distress or discomfort, a lack of knowledge, their feelings of personal discomfort, or insecurity and organizational policies. Similarly (25) noted personal discomfort with sexual topics and feeling unprepared to discuss it with patients among African nurses while 51% in (6) and the majority in (22) preferred to discuss it with a nurse practitioner. On the contrary, doctors were preferred (88.8%), followed by nurses (34%) (42). Nurses and doctors should maximize this important privilege.

The majority (245; 82.2%) in this study agreed that the patient should initiate sexuality discussion, however, 5.4% tried discussing sexuality with their caregivers while 94.6% had never. This might be due to the cultural setting where sexual matters are rarely discussed openly or the patients and caregivers were not skilled (43). Similarly, (44, 28) stated that cultural values and beliefs where sexuality is viewed as a highly personal matter hindered patients from discussing sexual problems. Similarly, cultural barriers, stigma and discrimination affected African nurses' conversations about sexuality with cancer patients in contrast to their Canadian counterparts (25). Respondents in (26-27, 14, 40) desired that the providers should initiate sexuality conversations while (23) opined that members of the health care team don't always ask about sexuality during check-ups and treatment visits thereby depriving patients of

enough information, support, or resources needed to deal with sexual problems. The health care team should be intentional about incorporating sexuality education in assessment protocols (43).

The relationship challenges faced by cancer survivors were anxiety about the sickness, depression about the loss of body parts, and difficulty performing roles as mother and wife or a father, husband and breadwinner. Following diagnosis and treatments of cancer, 30% of the participants were avoided by their partners causing tension at home. This could be due to the importance attached to body parts and the loss of body parts could be traumatising, affecting self-image and self-esteem. Partners may see their spouses as not complete. Increased tension in the home and sexual and emotional detachment from spouses that resulted in guilt feeling and frustration were reported by (26, 15). Chinese respondents (44) agreed that fatigue, physical problems and lack of interest affected sexual activity. All these could be avoided or reduced and more affectionate relationships and better outcomes are achieved when healthcare professionals talk to patients about cancer, its treatment and sexuality (11, 15).

Clinical Implications for Practice and Research

Cancer patients needed information on cancer and sexuality. Patients may not open up discussions about sex in the course of the battle for survival therefore professionals should encourage patients through prompts and open-ended questions. Discussing sexuality is very important to these patients and they would want to have some information/materials on sexuality and cancer, therefore, nurses should include such in the assessment protocols.

Study Limitation

Discussing issues about sex and sexuality with patients struggling with cancer and its treatment was an uphill task. Most patients were reluctant to discuss such aspects they considered personal and confidential until they understood the relevance of the study.

Conclusion

Cancer and its treatment have sexuality challenges for the patients. This study identified unmet sexuality concerns of adult cancer patients, and their needs for sexuality information/education. They desired educational materials to enhance it. The provision of assistance in dealing with sexual problems associated with cancer diagnosis and treatment is an important component of care. Thus training on basic assessment techniques including communication skills in LMIC will improve nurses' routine assessment of sexual functions among cancer survivors.

Conflict of interest

The authors declare that they have no competing interests.

Author contributions

All the authors collaborated on the work.

Authors UAN, HCO and AAC designed the study and managed the literature searches

Authors UAN, HCO, AAC and UCJ performed the statistical analysis, wrote the protocol, and wrote the first draft of the manuscript.

Authors AAC, OAL, ACJ AND ON reviewed the first draft critically.

All authors read and approved the final manuscript.

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Availability of data

All information and data concerning this work are contained in this article but further inquiry can be obtained from the corresponding author on request.

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