



MAIDUGURI JOURNAL OF EDUCATIONAL STUDIES

MAJES

*A Publication of The Department of Education,
University of Maiduguri*



VOLUME 10, SEPTEMBER, 2017.

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Caregivers' Perception of the Consequences of Breast Cancer in Kwara State, Nigeria: Implications for Health Educators

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Abstract

Breast cancer is one of the most common cancers and the highest leading cause of death among women. This study investigated the caregivers' perception of the consequences of breast cancer in Kwara State. Differences in the participants' perception based on duration of care giving and level of education were also examined. This study employed a descriptive survey method. A sample of 100 women, who are caregivers, selected through purposive sampling participated in the study. A self-designed questionnaire titled Consequences of Breast Cancer Questionnaire, (CBCQ) was used for data collection. The validity of the instrument was done by experts in the Departments of Counsellor Education and Behavioural Science, University of Ilorin, Nigeria. The reliability of the instrument was established using split-half reliability method and correlation coefficients of 0.62 was obtained. The data were analysed using frequency counts, percentages and means and Analysis of Variance (ANOVA) at 0.05 alpha level. The findings revealed that caregivers perceived consequences of breast cancer to be depression, chronic pain, emotional distress and death. It was also revealed that there were no significant differences in the participants' perception of the consequences of breast cancer based on duration of care giving and level of education. Conclusion was drawn that the consequences of breast cancer are devastating therefore, health educators should train caregivers through organization of workshops, on how to handle the consequences of breast cancer, with the aim of helping women with breast cancer cope with the found consequences.

Keywords: Consequence; Breast cancer; Caregivers; Perception, Health Workers.

All over the world, the incidences of breast cancer have been increasing, particularly in the areas where low incidences were reported, such as Asia. Breast cancer is perceived by researchers (Mystakidou, Parpa, Tsilila, Katsouda and Vlahos, 2004) as reaching epidemic proportions. In 1985, worldwide incidence of breast cancer was estimated to be 720,000 cases per year corresponding to 99.0% of all cancers. It was also estimated by Cancer Fact and Figures (2005) that one million new cases occurred in 2002. Mortality rate from breast cancer has also increased during the past 60 years in every country (Alam, 2006). Worldwide, breast cancer is the most common invasive cancer in women. (The most common form of cancer is non-invasive). Non-invasive cancers are generally easily cured, cause very few deaths and are routinely excluded from cancer statistics. Breast cancer comprises 22.9% of invasive cancers in women and

16% of all female cancers (World Cancer Report, 2008). In 2012, it comprised 25.2% of cancers diagnosed in women, making it the most common female cancer (World Cancer Report, 2014).

In 2008, breast cancer caused 458,503 deaths worldwide (25.7% of cancer deaths in men and women together), (World Cancer Report, 2008). The incidence of breast cancer varies greatly around the world; it is lowest in less-developed countries and greatest in the more-developed countries. In twelve regions in the world, the annual age-standardized incidence rates per 100,000 women are in Eastern Asia is 18 years; South Central Asia, 22 years; sub-Saharan Africa, 22 years; South-Eastern Asia, 26 years; North Africa and Western Asia, 28 years; South and Central America, 42 years; Eastern Europe, 49 years; Southern Europe, 56 years; Northern Europe, 73 years; Oceania, 74 years; Western Europe, 78 years; and in North America, 90 years (Stewart & Kleihues, 2003). The number of cases worldwide has significantly increased since 1972, a phenomenon partly attributed to the modern lifestyles. Breast cancer is strongly related to age with only 5% of all breast cancers occurring in women under 40 years old. Out of the 41,000 diagnosed cases of breast cancer registered in England in 2011, about 80% of the cases occurred in women aged 50 or older (Olson, 2002).

It is worrisome that complex diseases such as cancer are fast emerging as an important health care priority for the future (Adebamawo & Ajayi, 2000). In Nigeria, breast cancer is the most common type of cancer in women. A retrospective review data of breast cancer for 10 years in the University of Maiduguri Teaching Hospital cancer registry revealed that a total of 4,216 cases of cancer were registered and breast cancer accounted for 93.9% (Adebamawo, Ogundiran & Adenipekun, 2005). In their study, there were 1,449 females and 72 males with breast cancer giving a female to male ratio of 20:1. Breast cancer is a very common disease in Nigeria. It is often associated with a poor prognosis for a variety of reasons for instance, finance (Arinola & Charles 2007).

Although, the occurrence of breast cancer has recently been unequivocally documented in Africa, there remain some doubts about its features and to what extent it is a problem in this environment whereas in the many developed countries of the world, consensus centers on early detection of breast cancer. Africa, specifically Nigeria, remains today the greatest repository of advanced primary breast cancer. It is unfortunate that most of the patients are presented at a later stage, either because the ministrations of the traditional healers (trado-medicalist) have failed or due to ignorance (Abazie, 2014). Olapade (2002) stated that "the five-year survival rate for breast cancer patients in the United States exceeds 85 percent, in Nigeria it is 10 per cent. Cancer awareness, even among physicians is low, and how much more among women who are not health professionals. This implies that, there is need to boost the awareness of breast cancer in Nigeria. Okobiah (2006) reported in a study that late

presentation of patients at advanced stages when little or nothing can be derived from any form of therapy is perceived to be the hallmark of breast cancer death in Nigerian women; death has also perceived to be the greatest consequence of breast cancer. This is indeed a worrisome trend and it appears to be the norm in Nigeria. Unfortunately, till date in Nigeria, there is no effective therapy that is able to cure breast cancer except divine intervention especially, if it is not detected early, Okobiah (2006). According to Sainsburg, Anderson and Morgan (2000), the consequence of breast cancer include:

Hair loss: Some women lose their hair based on the stage of the disease and the type of treatment they are given. Some women notice only thinning of their hair, others lose their hair completely. Some lose their hair suddenly while others notice a more gradual loss a few weeks after starting treatment. Sometimes eye lashes and eye brows fall out.

Weight gain: Some women with breast cancer gain weight because of several factors; lack of activity, emphasis on eating and medicine.

Weakness and fatigue: Weakness and fatigue can have many causes, including the treatment, worry or depression, not eating, severe pain, inactivity, and low blood count.

Other consequences: It has also been stated by Leydon, Boulton, Moynihan, Jones, Mossman, Boudioni, McPherson (2000) that the effects of breast cancer are brain loss, memory loss, mouth sore, fatigue, depression, chronic pain and untimely death. Sainsburg, Anderson and Morgan (2000) reported that the most serious impact of breast cancer is loss of life and this is largely an effect of late diagnosis. They expressed that when breast cancer is not noticed at early stage, it moves to other parts of the body, therefore causing severe aches and chronic body pains.

Many women with breast cancer rely on caregivers to take care of them. Caregivers, according to the American Cancer Society (2014), are people who are paid or unpaid to assist a person who is incapacitated as a result of one sickness or another. A caregiver helps the sick person with his or her activities such as cooking, washing of clothes, bathing etcetera. Caregivers take care of people with chronic illness such as breast cancer, to manage medication and talking to doctors or nurse on their behalf. The roles of caregivers are being increasingly recognized in Nigeria as a person with chronic illness cannot do much for him/herself. Caregivers may be educated but they are not usually trained to give specific care; they are close friends, spouse, and family members among others. A caregiver is aware of the condition in which the woman with breast cancer is and many times, they are regarded as the 'lifeline' of the person with breast cancer.

Duration of care giving and level of educational qualification have been concluded to have impact on the caregivers' experience, discharge of duties, their perceptions and issues concerning the person receiving care (Schumacher, Stewart, Archbold, et. al., 2008). Duration of care giving refers to the length of time that caregivers have been rendering care to the person receiving it (American Cancer Society, 2017). It is

believed that the longer the duration of care giving, the better the knowledge of an ailment and the better they can express feeling about such ailments (National Cancer Institute, 2017). Levels of educational qualification of caregivers go about their roles as caregivers. Caregivers who are highly educated would be more enlightened than those who have low education (Glajchen, 2004). This can as well affect caregivers' perception and expression of the condition of the one receiving care. This is the more reason this study focused on the caregivers' perception of the consequences of breast cancer on the bases of duration of care and educational qualification.

Moreso, ignorance about the consequence of breast cancer, late detection of the disease and late presentation of patients for treatment are the major causes of death from breast cancer in women (Cancer Fact and Figures, 2005). According to the Center for Disease Control and Prevention (2005), 181,646 women were diagnosed with breast cancer and 41,619 women died from breast cancer in the United States in 2003. The average mortality rate for females with breast cancer was 25.5% (2000-2004) worldwide. This disease has also been estimated to have high rate of incidence of morbidity and mortality in Nigeria. With all these put together, this study investigated the caregivers' perception of the consequences of breast cancer in Kwara State.

Education is a key to human existence and nothing has been able to replace education in every society (Kumar, 2012). Education refers to a process of facilitating learning or the acquisition of knowledge, skills, values, beliefs and habits (Aikman, 2003). Education frequently takes place under the guidance of educators. Health education is any combination of learning experiences designed to help individuals and communities improve their health by increasing their knowledge or influencing their attitude (WHO, 2017). Health educators on the other hand, teach people about behaviours that promotes wellness. They develop and implement strategies to improve the health of individuals and communities (Bureau of Labour Statistics, 2016). It is therefore hoped that the findings of this study would have implications for health educators.

Purpose of the Study

The purpose of the study was to investigate caregivers' perception of the consequences of breast cancer in Kwara State. The study also sought to find out whether moderating variables of duration of care giving and level of education of caregivers influence the participants' perceptions of the consequences of breast cancer. Furthermore the study aimed to bring forth the implications of the findings to health workers.

The study hypothesized that there is no significant differences in the caregivers' perception of the consequences of breast cancer in Kwara State due to their duration of care giving and also due to their levels of education

Method

Design

Descriptive survey research design was adopted for the study. The descriptive survey design, allows a researcher to employ a questionnaire and or an interview, to determine the opinions, attitudes, expressions and perceptions of people of interest to the researcher (Daramola, 2006). Descriptive survey methods have the advantage of covering a wider scope because a great deal of information can be collected from a large population. Descriptive survey also allows for generalization of the entire population. Since the present study focused on the caregivers' perception of the consequences of breast cancer, the researchers considered the descriptive survey appropriate for a study of this nature.

Participants

A sample of One hundred (100) women who are caregivers in a Teaching Hospital in Kwara State, participated in the study. For adequate representation of caregivers across the State, the purposive sampling technique was used to select the University of Ilorin Teaching Hospital (UITH) out of all the hospitals and health centres in Kwara State. This is because, caregivers of patients with breast cancer can easily be found in this hospital. The purposive sampling procedure was also used to select caregivers that the researchers met in the hospital as at the point of collecting data and who consented to participate in the study. From the selection of the participants, 32.0% of the respondent have given care for less than 1 year, 56% have given care for upward of 1-3 years while 12% of the participants have given care for women with breast cancer for 4 years and above. Similarly, 43.0% of the participants chosen have either Primary or Secondary School Certificate, 37.0% have either NCE/OND educational qualification while 20.0% of the participants have either HND/1st degree/Master's educational Qualification.

Instrumentation

The instrument used to collect data for this study was 'Consequences of Breast Cancer Questionnaire' (CBCQ) which was self-developed. The instrument was divided into 2 sections: A and B. Section A sought demographic information of the participants while section B elicited information on respondents' perception of consequences of breast cancer. There were 15 Statements to which the participants were requested to respond to according to their perception of the issue raised in questionnaire. The validity of the instrument was done by experts in the Departments of Counsellor Education and Behavioural Science, University of Ilorin, Nigeria. The reliability of the instrument was established using split-half reliability method and correlation coefficients of 0.62 was obtained. The scoring of Section B of the instrument was done

as follows: Strongly Agree = 4; Agree = 3; Disagree = 2; Strongly Disagree = 1; Undecided = 0. The mid score is 50% therefore; any score of 50% and above indicates the participants' perception of the consequences of breast cancer while, scores below 50% indicates that participant's do not agree with the items to be some of consequences of breast cancer.

Procedure

The Consequences of Breast Cancer Questionnaire (CBCQ) was administered by the researcher with the help of two trained Research Assistants. The researchers and the Research Assistants explained the purpose of the study at the beginning of the administration. The participants were given enough time to fill the questionnaire and items that were not clear to the participants were carefully explained to them. The inventory was collected from the participants immediately they completed filling it.

The demographic data obtained were analyzed using the frequency count and percentages. The items on perceived consequences of breast cancer were also scored using percentages and rating rank order while, significant differences due to duration of care giving and educational levels of participants were analysed using Analysis of Variance (ANOVA) at 0.05 level of significance.

Results

The caregivers perceptions of the consequences of breast cancer was presented first, followed by differences in perception due to duration of care giving that of levels of education

Table1
Percentage and Rank Order of the Caregivers' Perception of the Consequences of Breast Cancer in Kwara State.

Perceived Consequences of breast cancer	%	Rank order
Depression	79	1 st
Death	77	2 nd
Distress	76	3 rd
chronic pain and suffering	72	4 th
physical defect	70	5 th
emotional of instability of the children	69	6 th
bone loss	67	7 th
poor financial strength of the family	62	8 th
Blindness	61	9 th
brain loss	60	10 th

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Poverty	60	10 th
Divorce	57	12 th
infidelity on the part of the husband	56	13 th
hair loss	54	14 th
social alienation and rejection	52	15 th

Table 1 shows the mean percentage and rank order of the caregivers' perception of the consequences of breast cancer in Kwara State. All the items on the table have mean scores above 50% therefore. It can be concluded that caregivers perceived depression, death, chronic pain, and distress physical defect as the top ranking consequences with % ranking from 79% down to 70%, and poverty, divorce, infidelity on the part of the husband, hair loss and social alienation and rejection as the least consequences with % ranging from 60 to 52 respectively

Table 2

Analysis of variance (ANOVA) on the Caregivers' Perception of the Consequences of Breast Cancer in Kwara State Based on Duration of Care giving

Variable	Sum of square	df	Mean square	Cal.F.	P-value
Between groups	1.776	2		0.10	0.34
Within groups	799.571	97	0.888		
Total	801.347	99	8.243		

Table 2 shows the calculated F. of 0.10 and a p-value of 0.34. Since the calculated p-value is greater than 0.05 level of significance it means that there is no significant difference in the caregiver's perception of the consequences of breast cancer based on their duration of care giving.

Table 3

Analysis of variance (ANOVA) on the Caregivers' Perception of the Consequences of Breast Cancer in Kwara State Based on levels of Educational Qualification

Variable	Sum of square	df	Mean square	Cal. F	p-value
Between groups	8.089	2	4.044	0.49	0.08
Within groups	793.258	97	8.178		
Total	801.347	99			

Table 3 shows the calculated F. of 0.49 and a p-value of 0.08. Since the calculated p-value is greater than 0.05 level of significance. This means that there is no significant difference in the caregiver's perception of the consequences of breast cancer based on their educational qualification.

Discussion

Result reveals that the caregivers perceived the consequences of breast cancer as: depression, death, chronic pain, distress, brain loss, physical defect, blindness, etc. This conforms the findings of Jerry (2002) which showed that breast cancer, when not diagnosed at any early stage can invade other parts of the body therefore causing severe aches and chronic body pains. This finding also supports the findings of Leydon, Boulton, Moynihan, Jones, Mossman, Boudioni and McPherson (2000) which showed that the aftermath of breast cancer are brain loss, memory loss, mouth sore, fatigue, depression, chronic pain and untimely death. The findings of this study could be as a result of the fact that cancer is one of the leading causes of death. Cancer, when presented in the hospital at a later stage can have consequences that can be devastating; these could be severe enough to cause chronic pain and shortened life.

The duration of care giving does not affect caregiver's perception of the consequences of breast cancer. This implies that caregivers of different length of years (duration) of taking care of the woman with breast cancer did not express the consequences of breast cancer differently. This is in support of the findings of Ademawo, Ogundiran and Adenipekun (2005) which revealed that length of time that caregivers engage in the care of persons with breast cancer, does not affect their expression or perception of consequences of breast cancer. Although, this negates the submission of National Cancer Institute (2017) that duration of care giving influences the expression of caregivers. The reason for the finding of the present study could be that the consequences of breast cancer are not hidden, and does not depend on the duration at which a caregiver is with the patient, before the consequences are noticed.

Educational qualification of caregivers does not influence their perception of the consequences of breast cancer. This implies that caregivers irrespective of their educational qualifications did not perceive the consequences of breast cancer differently. This finding negates that of Glajchen (2004) and Parkin, Bray and Devesa (2001) which showed that perception of those taking care of women with breast cancer differs based on educational qualifications. This finding of the present study could be that, the consequences of breast cancer of a life threatening disease such as breast cancer are enormous. Therefore, caregivers even with different educational backgrounds would be able to perceive them.

Conclusion

The findings of this study revealed that the caregivers perceived the consequences of breast cancer as depression, death, chronic pain, emotional distress, and brain loss among others are the consequences of breast cancer. Duration of care and educational qualification of caregivers did not significantly influence their perception of the consequences of breast cancer in Kwara State.

Implications of the Findings to Health Educators

The findings of this study imply that health educators should be ready at all time to pick up the challenge of educating people in the society on the different kind of ailments and the management of such. Health Educators need to guide and educate women rightly on the early presentation of breast cancer in the hospital and the management of its consequences. There is the necessity for health educators to float programmes which include the teachings of diseases such as breast cancer to all people; so as to help in the prevention, early detection and management of the disease.

Health educators need to take up the challenge of creating awareness by organizing programmes on radio and television to enlighten the entire populace on how to manage the consequences of breast cancer so as to improve recovery and prevent death, also with the aim of reaching people of different ages, gender and races. Health educators should give counselling on various consequences of breast cancer to every of their clients, hoping that the ailment could be prevented. Health educators should give adequate training to caregivers so to be able to better attend to the needs of women with breast cancer in managing the consequences of the disease. Level of education of caregivers and the duration of the care they have given should be disregarded when training them.

Recommendations

In view of the findings, health counsellors should liaise with Government on how to organize programmes on television stations, radio stations, seminars and conferences; to disseminate information to the entire populace on the consequence of breast cancer as lack of awareness has been noted in literature to be one of the reasons for the death of people having of breast cancer. Government should support women with breast cancer by collaborating with NGOs, social workers and training caregivers adequately to provide appropriate care for them. It is possible that when people who are sick are shown adequate care and support, recovery is enhanced. Efficient and up to date pain-relief or recovering machines and equipment should be provided in hospitals to ameliorate the consequences of breast cancer. Health workers should sensitize women on regular medical check-up and should help in referral services. They should play a

role in self management program by supporting self-management of women with breast cancer

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