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SOCIAL CAPITAL: AN EXPLORATIVE INVESTIGATION OF EXPERIENCES OF WOMEN WITH BREAST CANCER

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ABSTRACT

Breast cancer is the most common cancer in women worldwide. Following diagnosis and treatments, breast cancer patients often find themselves vulnerable and in need of social capital. However, social capital has received little attention when designing behavioural interventions for breast cancer. The aim of this study is to describe breast cancer patients' experiences of social capital while managing their illness. The study was non-experimental in design. Twenty-nine women with breast cancer, who were receiving treatment, that consented to participate were purposively recruited for the study. The Data were content-analysed using free narrative. The data show that relatives, spouses and friends play important role in providing social capital. Supportive behaviours through the provision of emotional support, such as empathy, and the provision of instrumental support, such as paying for medications and helping patients apply drugs, aid patients in managing and coping with the breast cancer. Social capital through civic provision and individual efforts alone, without considering social network, cannot yield a desirable result in the process of managing breast cancer. Health care interventionists should identify and capitalize on socio-dynamic pathways involved in social capital in formulating policy for managing breast cancer.

Key words: Breast cancer, patients, relatives, spouses, empathy,

INTRODUCTION

Social capital can broadly be defined as the structured social networks, trusting relationships and cultural norms that act as resources for individuals and facilitate collective action (Coleman 1998). However, social capital has not been given much attention when designing behavioural interventions for breast cancer (Salonen et al 2013). Breast cancer is one of the most common health challenges among women worldwide. It is a global disease with significant burden and its incidence continues to rise especially in the sub-Saharan Africa. About 92,600 cases of breast cancer and 50,000 breast cancer deaths were recorded in Africa in 2016 (Froude et al 2017). The World Health Organization estimates that about 250,000 cases of breast cancer are seen each year in Nigeria. Of these, nearly 10,000 deaths occur annually. Nigeria has the highest number of death from breast cancer in Africa (Akintunde et al 2015). Although there has been remarkable progress in reducing the frequency of breast cancer worldwide, women with breast cancer continue to die each year despite the availability of feasible, evidence-based solutions (Hinzey2017). Meanwhile, Community participation and socio-economic rehabilitation which are crucial elements in breast

control have remained weak, and response or behaviour towards those suffering from breast cancer is characterized by avoidance, insult and rejection (Erickson 2008).The literature indicates that social capital impacts on a person's perception of whether or not she can influence her own health (Mohseni2007).

The relevance of social capital in managing breast cancer has long been a controversial issue to health researchers. Studies have shown that social capital intervention for breast cancer management has focused more on structural components. Jones (2015) reported that social capital initiated for breast cancer emphasize on efforts of civic organization that focus on screening how to curb the spread and treatment of the disease. Jones also argued that social capital, when measured by structural and civic provision devoid of social support, would have little impact on breast cancer management practices. Social capital through providing material resources could not independently mitigate breast cancer challenges without highlighting the influence of significant others in the pathway to care (Messinel et al 2004). There was mixed evidence in few studies that highlighted the influence of social capital on breast cancer management, perhaps due to differing measurement approaches (Dragnet and Hamoudeh 2017). Browall et al (2006) saw no association between instrumental and informational support in the management of breast cancer. Lice et al (2003) found a negative association between social network index scores and routine mammography in the treatment of women with breast cancer. Also, Weedron (2007) reported that civic mobilization, but not church and influence of social support, increased breast cancer screening participation in the management of breast cancer. However, critics have questioned whether social capital adds anything new to the field of social networks and management of breast cancer, or if it is like 'pouring old wine into new bottles (Barco et al 2016). A common critique of social capital measurement and its application to breast cancer management is that there is no uniform measure, instead a variety of measures have been used in the pathway to managing breast cancer complex (Raupach & Hiller 2002). Studies have indicated that breast cancer survivors experience greater physical pain and increased risk of depression during the recovery process if they lack close social connections prior to treatment and after (Hinzey 2017;.Jones 2015). A study from Tasmania, Australia, showed how neighbourhood context and social support reduced the risk for poor self-rated health among women, but not men. In another version, Raupach (2002) found that living in a neighbourhood with low levels of trust and integration increased the odds ratio for poor self-rated health.

Also, studies by Dragnet and Hamoudeh (2017) had shown that women are more likely to withstand breast cancer and its aftermath if they have at least one supportive confidante.[11] Breast cancer can be particularly difficult for patients who have yet to have built social support networks within their own family. Patients or sufferers often need added help in coping with issues associated with breast cancer and its treatment. By focusing attention not only on the physical aspects of this condition,

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but also on the psychosocial effects of breast cancer on these vulnerable individuals, Messinnel (2004) asserted that without these social connections, patients may suffer from lack of essential care at home during the critical treatment phases and after breast cancer surgery. Integrating questions about the degree of social support available to patients as part of the intake process could be an excellent first step towards decreasing mortality rates and improving the quality of life among these at-risk patients (Messinnel (2004).

Today, aggregated measures of individual trust and participation are the most commonly used measures of collective social capital (Macinko 2001; Lynch 2000). The improvement and maintenance of health is dependent not only on individual behaviours, but also on the behaviours of significant others and the ability for fruitful communication within social networks (Hendryx2008).Matthew (2003) has stressed the need for more area-based indicators of collective social capital. Studying individual characteristics may not be adequate to explain health outcomes and health behaviours. Studying "neighbourhood context" may lead to a more informed analysis (Kawachi 2000). In the social capital framework, the way we organize our societies, the amount of contribution we make towards interaction between people, and the degree of trust and cohesion in communities are likely to be the most important determinants of our health (Clarke et al 2003)

To date, the literature documenting the impact of social capital on the management of breast cancer has been limited (especially in Nigeria). Many of the studies reported mixed findings, making impact of different levels of social capital on breast cancer management difficult to ascertain (Dragnet V & Hamoudeh 2017; Clarke 2003; Yoo et al 2010). Some studies have methodological limitations, particularly the lack of qualitative analytic methods, and measures of health outcomes have been relatively poor (Barco 2016). There is also little information about the way social capital changes during the course of experiencing breast cancer (Hinzey 2015). Previous studies that highlighted the importance of social capital in breast cancer management largely focused on civic provision and individual's efforts, with little or no consideration of the efforts of "significant others" within the context (Dragnet & Hamoudeh 2017; Clarke 2003; Yoo et al 2010). Against this background, this study explored how family members, relatives, friends, and neighbours participate in respondents' management of breast cancer; how they engage in behaviours that are supportive, controlling and encouraging. Supportive behaviours included the provision of emotional support such as empathy and alleviation of breast cancer related distress; the provision of instrumental support such as paying for medications and helping respondents apply drugs. This study will help to identify socio-dynamics pathways to breast cancer management as well as generate ideas for further researches that would provide more empirical evidence for policy direction in the formulation, design and implementation of workable programmes that would promote breast cancer management.

THEORY

Social Resource Theory

The study is anchored on the theory of social resource, which makes explicit the assumption that resources embedded in social connections play important roles in the interaction between social structure and individuals. More specifically, the theory explores how individuals access and use social resources to maintain or promote self-interests in a social structure that consists of hierarchically related and organized social positions, in terms of valued resources. One of proponent and advocator of social resource theory is Lu-Lin Cheng. He stated that resources are goods, material as well as symbolic, that can be accessed and used in social actions. Of particular interest are the valued resources – resources consensually considered as important for maintaining and improving individuals' chances of survival as they interact with the external environment (Lu-Lin Cheng 1986).

Lu-Lin Cheng classified resources in two categories: personal resources and social resources. Personal resources are resources belonging to an individual; they include such ascribed and achieved characteristics as gender, race, age, religion, education, occupation, and income as well as familial resources. These resources are in the possession and at the disposal of the individual. Social resources, on the other hand, are resources embedded in one's social network and social ties. These are the resources in the possession of the other individuals to whom ego has either direct or indirect ties (Lu-Lin Cheng 1986).

It has been argued that social resources are accessed and mobilized in a variety of actions by an individual to achieve instrumental and/or expressive goals. Thus, the theory contains, first, propositions postulating the effect of social resources, and, secondly, propositions postulating causes of social resources. The strength-of-position hypothesis implies an inheritance effect. A given position of origin in the hierarchical structure in part decides how well one may get access to better social resources embedded in the social structure. It is a structural factor and independent of individuals in the structure, although individuals may benefit. On the other hand, the strength-of-ties hypothesis suggests the need for individual action. Normal interactions are dictated by the homophile principle: the tendency to engage in interaction with others of similar characteristics and life-styles. It has been hypothesized that in contrast to instrumental actions, expressive actions would be more effective if ego and the alter share similar traits and experiences. The argument is that homophile (sharing similar characteristics and life-styles) increases the likelihood of the alter understanding the emotional stress experienced by ego. Thus, the expectation is that strong ties, rather than weak ties, may provide the more desirable social resources for expressive actions.

In applying social resource theory to our study, social capital constitutes resources embedded in one's social network and social ties. The social resources are structural and civic provision as well as emotional support, and instrumental support, which are accessed and mobilized in a variety of actions by individual to achieve instrumental and/or expressive goals. Based on this study, breast cancer patients accessed social resources through civic organization, but to larger extent through family, spouse and friends in order to achieve expressive goal, that is, to be able to manage their illness.

METHODS

This study used a non-experimental research design, involving a cross-sectional survey carried out among women receiving breast cancer treatment at University Teaching Hospital, Lagos, Nigeria. Qualitative method of data collection was used because it enables us to achieve a deep understanding of how and why people view issues in particular ways and the factors that impact upon their experiences. Also, a qualitative research method facilitates respondents to speak, thus enabling the disclosure of insights, and resulting in original, deep and rich information. Selected respondents were interviewed individually since the study used in-depth interview guide (IDI). The respondents were purposively selected based on the criteria that they are receiving breast cancer treatment, gave informed consent to be interviewed, and were stable to interact with the interviewers. This enabled us to draw or reflect on their personal experiences. It was assumed that the respondents would have had varied experiences on the objective of the study. After the respondents were identified and approached, their informed consent was sought for interviews. Verbal informed consent was obtained from respondents after the objective of the study was explained to them.

Questions asked include "How have your relatives, spouse and friends support you in process of managing the illness?"; "Does your relationship with your people facilitate emotional and instrumental support?"; "Based on your present condition, does it affects your social activities?" ;"How does your present condition affect your relationship with your relatives, spouse and friends?". We did not limit ourselves to the interview guide alone; questions were allowed to flow from the nature of information or responses received from the respondents. The interviews were audio-taped and the information was transcribed verbatim and in some cases translated from local languages into English. Words or statements with similar interpretation were grouped into categories. Similar categories were grouped into themes and sub-themes. The results were presented using direct quotes from the data.

The process of analysis began by doing open coding and microanalysis. This process entailed deep routine interaction with data. All generated data were crosschecked, and sorting of the data according to the research objectives involved the writing of study objectives on separate sheets of

paper, which were referred to as "objective cards" (this enables the researcher to constantly check the cohesion of his findings in line with the aims and outputs of research – one could call this a "running point" of reference). We employed an iterative analysis approach in finalizing the code list to reflect a nuanced focus on the study themes. On the other hand, direct quotation of responses (that indicate respondents voices), which entails verbatim reporting of opinions, idioms, and proverbs that support important findings in the data were done. The direct quotations of informants were later translated into English for proper reporting.

RESULTS

Family Cohesion

Perceived emotional bonding such as family cohesion is very important for patients living with cancer because they generally tend to feel stigmatized or isolated. Family cohesion reduces the stress from social isolation and stigmatization that often accompanies cancer, creating a feeling of comfort and allowing patients to focus on coping with their illness. Cancer has a serious impact on the entire family and does not occur as an isolated experience. Family cohesion has been seen as one major surviving factor for cancer patient. The more bonded and helpful the families of a cancer patient are, the more the longevity of the life. A strong emotional bonds measured by family cohesion are expected to promote family support. The majority of the respondents were of the view that their families have been like a shield to them, and are very caring. Their husbands role have never be left out blank. Coupled with the role of a husband, they do play the role of a father to them. Below are some of the responses of some of the respondents:

Relationship with Spouse and Children

The role of spouse in the management of breast cancer was stressed by some of the respondents. Marriage is the ultimate bond between two partners. You made a vow to love one another for better or for worse. Relationships require work and commitment to keep your love for another strong, and marriage is no exception as demonstrated in some of the responses on relationship with spouse:

> We still interact very well. He's very caring and the children too are caring. One of them even brought me to the hospital; he's in the car with the driver because I can't drive myself.(59 years/Teacher)

Another respondent had it that her spouse has been a very nice person. According to her:

> My husband has been nice. I have never seen a man like him. He takes me to the hospital each time I need to go. Even when I was doing radiotherapy, you won't believe that this man left the house as early as 03:00am to Eko hospital just to register my name so that I would be one of the first persons to be attended to by the doctors.

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> There's no medicine or food that is recommended by the doctor that he doesn't buy for me. He even buys and blends fruits for me to take. In fact, he's one in a million. (54 years/Self Employed)

The data show that having a positive relationship with children is one essential social capital to their emotional and social growth as illustrated in the responses of some of the respondents:

> I am recently staying with my child, I have left home. My child who is a nurse told me to come and stay with her so she could be taking care of me; my husband comes here to see me once in a while because we are at Owode, Ife road. (65 years/Trader)

However, some of them asserted that even though their husbands and family members do not have money or a good financial backing, they still show love and support them with the little they have. According to one of the respondents,

> My husband is trying, although he has nothing and there is also no money, he is caring and helpful.(55 years/Trader)

Unlike the previous respondents, a respondent affirms that her husband's attitude and interaction with him has changed since the inception of the illness. According to her:

> The interaction has changed a bit. It might be due to the illness, I don't really know; I can't really say. Actually, I have been away since; I am just coming back from a place. We have not really been together. I am based in Warri and I had the treatment in Ife, so I have been in Ife since. (53 years/Civil Servant)

Role of Membership in Women Social Group

The study of human society is essentially the study of human groups. Society consists of groups of innumerable kinds and variety. No man exists without a society and no society exists without groups. Groups have become a part and parcel of our life. The role of membership of women in social groups plays a significant part in their lives during the time of needs. Some groups tend to help and uplift the other member that is down. They do come to victim's aid financially and also encourage them. Most of the respondents do not belong to a social group, but for those who belong are benefiting from such associations as stated in some of their statements.

> They encourage me, and give me financial support, even if it is just a little. (53 years/Civil Servant)

Another respondent stated that:

> Things have changed since I don't have money again. there is a saying that if you don't have money, you don't have anybody. They did not assist me. They don't know about the sickness, I did not tell them. (55 years/Trader)

Another respondent reinforced the view, but conceded that much of the support comes from her spouse.

> They sometimes support me financially but mostly it's my husband that carries out the financial aspect of my treatment. (41 years/Teacher)

Non-disclosure to Members of Social Group

The finding from this objective is in cognizance of the literature review. According to Harward scientist Robert D. Putnam, in his book Bowling Alone (New York, NY: Simon & Schuster, 2000), "As a rough rule of thumb, if you belong to no groups but decide to join one, you cut your risk of dying over the next year in half." So powerful is the link between health and connection such that those with poor social relationships are 50 per cent more likely to die than those with just "adequate" social relationships. Belonging to a women group uplifts the spirit and also promotes good management of breast cancer.

Importance of Support from Relatives

Effective support from relatives can make a considerable difference to the people who are dying, helping to allay fears, reduce anxiety and minimize suffering in bereavement. It is apparent that emotional and instrumental supports are provided in the first phase of the treatment. The main sources of support include the spouses, family members and friends. Spouses provide emotional support, but mainly provide instrumental support, while family members and friends are the most important sources of emotional support. Family members are especially important sources of social support in the lives of cancer patients. Most of the respondents acknowledged that their relatives have been supportive, even though some of them may not contribute financially. Below are some of the responses respondents gave on family support:

> My mother has been very supportive. As old as she is, she tries her utmost to help me. She stood by me during my surgery. Even though she can't do much, she helps me direct so many affairs that I'm supposed to direct. And the children too really supports by following me to the hospital and bringing me food. My children are boys, yet they go to the market to buy things and cook for me. The back door in my office was bad and they helped me to fix it up. (59 years/Teacher)

Another respondent stated:

> My relatives have been wonderful. Ah! I never knew they loved me like this, especially one of my brothers. In fact, I said for the sake of this my brother, God should allow me to live. He wanted to take me out of the country for my treatment, but my instinct told me to do it here in Lagos. He's been supportive. When my hospital bills were mentioned, he'd tell my husband to split it into two and he'd contribute half of it. He's been nice and caring. They wake me up every morning with prayers. I never knew they loved me this much until I became sick. **(54 years/Self Employed)**

On the other hand, a respondent stated that there were no support from relatives, and the only form of worthy assistance she received were those provided by her children. She stated that:

> The only support I get is from my children. I have two children, a boy and a girl. My daughter is 33 and my son is 30. **(57 years/Teacher)**

Some of the respondents also asserted that they do not only get social support morally, emotionally and psychologically, but also financially. According to a respondent:

> It's my husband that has been supportive, besides my salary. Few friends supported me in their little way. My best friend in my place of worship really supported me. She sometimes brings food and money for me. **(59years/Teacher)**

Neighbours and Management of Breast Cancer

Today, most people with cancer are treated in the outpatient setting – they don't have to stay in the hospital. During this time they often need help, support and encouragement. Cancer survivors with strong emotional support from people and neighbours tend to adjust to the changes cancer brings to their lives, have a more positive outlook, and often report a better quality of life. A person with cancer needs support from friends and people around them. From the responses it was found out that some neighbours gave helping hands to victims of cancer around them. According to one of the elderly respondents:

> The only neighbour that is aware of the sickness has been sending series of information to me on social media, chatting and praying for me. When I'm less busy, I also visit her. **(63 years/Pensioner)**

On the other hand, the findings suggest that younger women were more predisposed to expressing their health status. This is reflected in the response of the youngest participant. According to her:

> People around me and neighbours have been good and helpful to me in terms of support morally, although they do not support me financially. **(27 years/Unemployed)**

Some neighbours and people around sometimes might not be of help to cancer victims. One of the respondents asserted that she doesn't relate with her neighbours, because the only person she can put her trust and confidence in is her husband. According to her,

> I don't really like being close to people. My husband is my everything. He's my friend, husband and everything. I only exchange greetings with my neighbours and if I have anything to give out to them, I do so. I was a very busy person. Most often, I'm in China and don't have time to visit anyone. But when the sickness came, they didn't know about it. They were pork-nosing and wanted to know but I didn't let them know. I don't want anybody to know. I'm keeping it to myself. **(54 years/Self Employed)**

Another respondent also averred that breast cancer as a sickness is something that should not be related to anyone because it frightens people and gives negative thoughts about victims to the people. According to her,

> We live normally because they are not aware of the illness. It is a sickness that is related to death. When you mention it, it scares people away from you so I felt there's no need. They will bring me down with their reactions so it's better I look onto God and help myself. **(57 years/Teacher)**

A respondent also alleged that she doesn't have time for anybody or play around with neighbours, but focuses only on God and stays alone. According to her,

> I don't have time for anybody; I only praise God in my quiet time. I sell, and when I come out early morning by 10 o clock, I do sell in retail or wholesale to traders who sell in schools. So, I praise God with my remaining time. I don't enter anybody's house. I stay alone. **(IDI/ 55 years/Trader/October, 2017)**

DISCUSSION AND CONCLUSION

This study explored how social capital influences the management of breast cancer. The results of this study constitute one of the ways in which attention has been given to social capital when designing behavioural interventions for breast cancer, contrary to earlier assertion by Salonen et al (Salonen et al 2013). Our result shows that family cohesion, through a positive relationship with spouse and children, is one major surviving factor for breast cancer patient in the study. According to respondents, this cohesion enhances emotional and social growth that facilitates family support that constitutes a shield for breast cancer patient. This finding is in line with Clark et al's (2003)

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assertion that the more bonded and helpful the families of a cancer patient care, the more the longevity of the life.

Aside from the support from children and spouse, extended family members also constitute a support to breast cancer patients. They are important sources of social support in the lives of cancer patients. Most of the respondents acknowledged that their relatives have been supportive, even though some of them may not contribute financially. This shows that support system goes beyond financial assistant. Spouses provide emotional support, but mainly provide instrumental support, while relatives and friends are the most important sources of emotional support. Effective support from relatives has made a considerable difference to the people who are dying, helping to allay fears, reduce anxiety and minimize suffering in bereavement. This finding corroborates previous studies which showed that women are more likely to withstand breast cancer and its aftermath if they have at least one supportive confidant (Sabado 2014; Yoo2010)

Our study shows that breast cancer patients also receive support from friends and neighbours around them. From the responses, it was found out that some neighbours give helping hands to patients of breast cancer around them. It was also discovered that some patient did not disclose their case to their neighbours to avoid being intimidated and ridiculed. This concealment might have some implication on the sufferer, as it will limit the neighbour's effort to support the patient. It further negates the aspect of social capital that emphasise trust, reciprocity, information, cooperation and cohesions. This is often detrimental to the health of the patient. This is in line with the arguments of previous studies that living in a neighbourhood with low levels of trust and integration increases the odds ratio for poor self-rated health. These neighbourhood characteristics might therefore constitute supporting environments and health-enabling communities.

Our findings also show that belonging to membership of women social group is one of social capital through which one receives support for breast cancer management. As man is a social animal, man is bound to derive mutual benefit from others. According to some of the respondents, belonging to a women group uplifts the spirit and also promotes good management of breast cancer through defined social relationships that enhance both emotional and instrumental support. It further promotes the health of the patients. This buttresses the assertion of Litaker that so powerful is the link between health and connection that those with poor social relationships are 50 per cent more likely to die than those with just "adequate" social relationships. Breast cancer can be particularly difficult for younger women who have yet to have built social support networks outside their own family (Frounde 2017). Social support networks necessitate social ties.
Social ties strengthen individual commitment to social support emphasized in social capital. Initially, the idea of describing social ties as a form of capital was simply a metaphor. This

metaphor "implies that connections can be profitable; like any other form of capital, you can invest in it, and you can expect a decent return on your investment." Social capital can advance social network interventions by acknowledging the risk for unequal distribution of investments and returns from social network involvement. Our results show how family members, relatives, friends and neighbours participate in respondents' management of breast cancer and how they engage in behaviours that are supportive, controlling, and encouraging. Supportive behaviours include the provision of emotional support, such as empathy and alleviation of breast cancer related distress, and the provision of instrumental support such as paying for medications and helping respondents apply drugs.

The findings of this study shift our orientation away from most conventional claim that civic provision and individual's efforts constitute an ideal social capital in the management of ill-health such as breast cancer management. However, this study does not rule out 'civic provision' and individual efforts as social capital, but shows that social dynamics through social support is very vital to complement civic provision in quest for management of ill-health, especially breast cancer. This is in line with the assertion of Yoo et al that the building of social capital must be considered as complementary, rather than a replacement of broader structural interventions (Hendryx2008). The existing social capital within a community, which is closely related to civic mobilization, sense of coherence, and commitment, can influence both the efficiency and effectiveness of a program. Therefore, the health effectiveness of a program may depend not only on the program itself and the individual participants, but also on community social capital. At the same time, social capital can be affected (preferably enhanced) by the implementation of a program. Health promotion interventions that target only individual behaviour have a less-than-expected impact on health outcomes. If the intervention is to be conducted in the community and is intended to target community residents, then the broader social context must be considered.

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