Access to health information, health literacy and health-related quality of life among women living with breast cancer: Depression and anxiety as mediators

Nuworza Kugbey¹,b,⁎, Anna Meyer-Weitz⁴, Kwaku Oppong Asante⁴,c

¹ Discipline of Psychology, School of Applied Human Sciences, University of KwaZulu-Natal, Durban, South Africa
² Department of Family and Community Health, School of Public Health, University of Health and Allied Sciences, Hochoe-Campus, Volta Region, Ghana
³ Department of Psychology, School of Social Sciences, University of Ghana, Legon, Accra, Ghana

A R T I C L E   I N F O

Article history:
Received 7 May 2018
Received in revised form 4 February 2019
Accepted 9 February 2019

Keywords:
Health literacy
Health information access
Health-related quality of life
Breast cancer
Ghana

A B S T R A C T

Objective: This study examined the direct and indirect influences of health literacy and access to health information on the quality of life among 205 women living with breast cancer in Ghana.

Methods: A cross-sectional survey design was employed. The interviewer-administered instrument included the health literacy scale, questions on access and satisfaction with healthcare information, depression and anxiety scale, and the Functional Assessment of Cancer Therapy-Breast Cancer.

Results: Access to health information and health literacy had significant indirect effects on quality of life through depression and anxiety. Whereas health literacy had direct influence on quality of life after controlling for other factors, access to information had no direct influence on quality of life.

Conclusion: Health literacy and access to health information improve quality of life in women living with breast cancer by reducing the levels of depression and anxiety. Depression and anxiety serve as possible mechanisms for the positive impacts of access to health information and health literacy on improved quality of life among breast cancer patients.

Practice implications: Health care providers need to ensure that the information needs of patients are met in oncology practice to reduce their negative emotional states which would lead to improved health and wellbeing.

© 2019 Elsevier B.V. All rights reserved.

1. Introduction

The information needs of persons living with chronic medical conditions such as breast cancer cannot be underestimated as quality and accurate information is critical for the optimal management of these conditions and improved quality of life [1–4]. The need for patients to be actively involved in their treatment decisions has resulted in high information needs among patients in developed countries where a relatively small power distance exists between patients and healthcare providers [2,3,5]. However, the case may not be the same in developing countries with greater power distance between the patients and healthcare providers. Power distance refers to the level of expected and accepted inequalities in society which influence the nature of interaction among people [6].

Cancer patients have been found to rely on varied sources of health information which influence their health outcomes and treatment decisions [7–9]. Personal doctors, oncologists, family and friends, mass media and the internet are some of the most commonly used information sources among cancer patients [10–12]. Unlike Western countries, evidence from studies conducted among breast cancer patients in Angola and Nigeria suggests little or no use of information from the Internet and support groups regarding breast cancer is utilized [12,13]. However, there is no available published literature on the sources of information accessed by women with breast cancer in Ghana to better inform health care delivery with regard to the information needs of patients.

Patient education in the Ghanaian context is impacted by patriarchy with most physicians being males, as reflected in the relatively large power distances which can be seen between patients and their healthcare providers [14]. This power distance is likely to impact on information sharing and subsequent access to health information. Therefore, it is important to understand the information needs of women living with breast cancer to better...
address their needs and thus, improve health care delivery. Much of the fears and uncertainties surrounding breast cancer treatment and outcomes may be lessened with changes in information sharing patterns between breast cancer patients.

Besides patients’ access to healthcare information, the level of satisfaction with the information received is equally crucial. The satisfaction with healthcare information has been found to be associated with increased quality of life and decreased levels of psychological distress [15,16]. However, inconsistent findings in this regard have been reported with some studies showing negative relationships between access to and satisfaction with healthcare information and patients’ health outcomes [17,18] or, no significant influence of healthcare information on patients’ levels of depression, anxiety and quality of life [19].

Access to healthcare information is linked to improved health literacy among patients [20–22]. Health literacy has been conceptualized as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [23]. Health literacy influences several health outcomes such as physical functioning, emotional functioning, healthcare utilization, key decision-making outcomes and self-care management among patients [24–30]. Poor or limited health literacy is associated with several negative outcomes such as poor patient-physician communication, poorer use of health care, poorer adherence and relapse [24,30–32], although some evidences suggest weak associations or mixed findings [33–35]. Some researchers have suggested that three plausible mechanisms connect health literacy to health outcomes in patients: access and utilization of health care, patient-provider relationships and self-care [36]. However, the mechanisms linking health literacy to quality of life among breast cancer have not been fully understood. Examining these mechanisms could help understand the role of health literacy in health-related quality of life among women living with breast cancer.

Studies reviewed showed inconsistent findings with regards to the direct influences of access to information and health literacy on quality of life. Specifically, the mechanisms that explain the influence of access to health information and health literacy are poorly understood. Examination of possible mechanisms could further our understanding of the influence of these factors on quality of life among women living with breast cancer. There are no studies in the Ghanaian setting addressing these issues despite the rising number of breast cancer cases and associated problems [37–39]. Therefore, this study examined 1) the main sources of breast cancer information among the women, their access and satisfaction with healthcare information and 2) the direct and indirect effects of health literacy and access to health information on quality of life among women living with breast cancer through depression and anxiety (which are significant risk factors for poor quality of life).

2. Methods

2.1. Participants and design

A cross-sectional survey design was used and participants were 205 women living with breast cancer and receiving treatment at a teaching hospital in Ghana. These participants were selected using convenience sampling technique. The participants had a mean age of 52.49years (SD = 11.49years) and a mean duration since diagnosis of 29.64months (SD = 38.75months). Majority of the women (67.8%) were married whereas the remaining 32.2% were either single, divorced or widowed. About 89% of the participants reported to have had some formal education. Majority of participants (61.2%) were employed and the remaining 38.8% were either unemployed or retired. A little over half (53.2%) of the participants had a monthly average income of GHC500 ($113) or less and 35.9% of the participants where on single treatment (Chemotherapy, Radiotherapy or Surgery) while 64.1% of the participants have received two or more treatment types.

2.2. Measures

The measures used in the study consisted of newly developed measures and adapted versions of original measures developed in Western countries for the Ghanaian context as outlined below:

2.2.1. Access to health information

A set of 8 questions were developed to measure the main sources of information on breast cancer. Examples included main sources of information, rating of overall access to information, use of information from non-healthcare professionals and type of information sought from alternative sources.

2.2.2. Information satisfaction index

Three questions were developed to assess women’s satisfaction with information. These items included satisfaction with the quality of information, amount of information from healthcare workers and satisfaction with how concerns are addressed. A 4-point Likert response format was used and total scores could range between 3 and 12 with higher scores reflecting higher satisfaction with information from healthcare providers. Internal consistency value of the Index was good (α =.87) in this study.

2.2.3. The health literacy scale

Health literacy was measured with 6 items adapted from the original Health Literacy Scale [40]. This was necessitated by results from pre-testing of the questionnaires which did not find all the items applicable to the Ghanaian context. Only 6-items were found relevant and this 6-item questionnaire was used in this study to measure overall health literacy. Items on the scale were “You have . . . 1) understood all the information you obtained, 2) shared your thoughts about your health with someone, 3) considered the credibility of the information, 4) checked whether the information was correct, 5) collected information to make decisions about your health and 6) used the information obtained in your daily life”. A 4-point Likert response format ranging from 1 (never) to 4 (often) was used as in the original scale with higher scores indicating higher level of health literacy and lower scores indicating limited health literacy. The total scores of the scale ranged between 6 and 24. In this study, the health literacy scale had a good internal consistency value (α =.80).

2.2.4. Depression and anxiety

These were assessed with the Hospital Anxiety and Depression Scale [41]. This scale consists of 14 items which measure depression (7items) and anxiety (7items) in patients. A 4-point Likert response with scored from 0 (not at all) to 3 (very often indeed) was used. The total score the subscales could range between 0 and 21 for anxiety and depression with higher scores indicating higher depression and anxiety levels. The scale had good internal consistency values of 0.90 and 0.82 for anxiety and depression subscales respectively.

2.2.5. Health-related quality of life

Health-related Quality of Life was assessed with the Functional Assessment of Cancer Therapy–Breast Cancer [42]. This scale consists of 37 items with 27 measuring quality of life from four domains (emotional well-being – 6 items, social/family well-being -7 items, physical well-being -7 items, and functional well-being -7 items) while 10 items measure other breast cancer-related concerns. A 5-point Likert response format was used with
responses ranging from 0= Not at all to 4 = Very much. The scale demonstrated good reliability in this study (α = .92).

2.3. Procedure

The study protocol was approved by the Humanities and Social Sciences Ethical Committee of the University of KwaZulu-Natal, South Africa, the Scientific and Technical Committee and the Institutional Review Board of the Kolele-Bu Teaching Hospital in Ghana. All ethical guidelines regarding the use of human participants were strictly adhered to in the data collection and management process. Prospective participants were recruited from the out-patients department of the Nuclear Medicine and Radiotherapy Department of the Kolele-Bu Teaching Hospital. After the objectives of the study were explained to the patients, informed consent was obtained from those who voluntarily agreed to take part in the study. The questionnaires were mainly interviewer-administered to the patients with few participants interested in self-administration.

2.4. Data analysis

Data analysis was done using SPSS 22 and preliminary analysis revealed that all variables were distributed normally. Pearson correlation coefficient was used to test the relationships among the study variables. The PROCESS Macro [43] add-on for SPSS was used to analyze the direct and indirect influences of access to health information and health literacy on quality of life through depression and anxiety. A percentile bootstrap confidence interval was used to determine the significance of the indirect effects with confidence intervals excluding zero regarded as significant [43].

3. Results

3.1. Sources, satisfaction and access to health information by women living with breast cancer

Results from Table 1 showed that women living with breast cancer relied on information about their illness from health workers (80%), television (66.8%), radio (53.7%), newspapers (13.2%), Mosque/Church (13.2%), community meetings (7.8%) and schools (3.4%). However, 33.2% of the women indicated that they sought information from non-health professionals and the information were mainly on treatment (83.6%), alternative therapy (65.7%), self-care (65.7%), symptoms (50.7%) and diagnosis/prognosis (46.3%). It was further observed that 93.9% of the women found the information from non-health professionals very useful for their illness. The result further showed that 89.8% of the participants were satisfied with the amount of information received, from health care professionals 91.7% were satisfied with the quality of health care information and 79% indicated that their concerns had been adequately addressed. Responses on access to health care information showed that only 7.3% of the participants rated their access to healthcare information to be poor.

3.2. Bivariate relationships among the study variables

As can be seen in Table 2, health literacy was negatively correlated with depression (r = -0.316, p < .01) and anxiety (r = -0.257, p < .01) but positively correlated with overall quality of life (r = 0.169, p < 0.05) and some dimensions of quality of life. Access to health information was negatively correlated with depression (r = 0.223, p < .01) but positively correlated with overall quality of life (r = 0.187, p < .01) and some dimensions of quality of life. Anxiety (r = -0.671, p < .01) and depression (r = -0.773, p < .01) negatively correlated with overall quality of life and all the dimensions of quality of life. Satisfaction with information only correlated significantly with anxiety (r = -0.162, p < .05).

3.3. Direct and indirect pathways from access to information and health literacy to quality of life

Results from the mediation analysis using ordinary least squares (OLS) path analysis, showed that access to health information had an indirect influence on quality of life through both depression and anxiety after controlling for health literacy. Increased access to health information predicted decreased depression (β = –1.186, t = –2.743, p < .01) and anxiety (β = –1.572, t = –2.994, p < .01) (See Fig. 1). Higher levels of depression (β = –3.581, t = –9.929, p < .001) and anxiety (β = –1.155, t = –3.887, p < .001) predicted decreased quality of life. A percentile bootstrap confidence interval for the indirect effect through depression (β = 4.247) based on 10,000 bootstrap samples was entirely above zero (1.575–7.186) and the indirect effect through anxiety (β = -1.815) based on 10,000 bootstrap samples was entirely above zero (.519–3.562). However, there was no evidence for a direct influence of access to health information on quality of life (β = .151, t = .092, p = .927).

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Access to health information among women living with breast cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variables</td>
<td>Frequency</td>
</tr>
<tr>
<td>Main sources of information&lt;sup&gt;1&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Television</td>
<td>137</td>
</tr>
<tr>
<td>Radio</td>
<td>110</td>
</tr>
<tr>
<td>Newspapers</td>
<td>27</td>
</tr>
<tr>
<td>Hospital (Doctors &amp; Nurses)</td>
<td>164</td>
</tr>
<tr>
<td>School</td>
<td>7</td>
</tr>
<tr>
<td>Church/Mosque</td>
<td>27</td>
</tr>
<tr>
<td>Community Meetings</td>
<td>16</td>
</tr>
<tr>
<td>Satisfaction with the amount of information from health workers</td>
<td></td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>5</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>16</td>
</tr>
<tr>
<td>Satisfied</td>
<td>156</td>
</tr>
<tr>
<td>Very satisfied</td>
<td>28</td>
</tr>
<tr>
<td>Satisfaction with the quality of information from health workers</td>
<td></td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>3</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>14</td>
</tr>
<tr>
<td>Satisfied</td>
<td>166</td>
</tr>
<tr>
<td>Very satisfied</td>
<td>22</td>
</tr>
<tr>
<td>Concerns adequately addressed by health workers</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>7</td>
</tr>
<tr>
<td>Somewhat</td>
<td>35</td>
</tr>
<tr>
<td>Very well</td>
<td>136</td>
</tr>
<tr>
<td>Absolutely</td>
<td>25</td>
</tr>
<tr>
<td>Sought information from non-health professionals</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>66</td>
</tr>
<tr>
<td>Type of information sought information from non-health professionals</td>
<td></td>
</tr>
<tr>
<td>Diagnosis/prognosis</td>
<td>31</td>
</tr>
<tr>
<td>Symptoms</td>
<td>34</td>
</tr>
<tr>
<td>Treatment</td>
<td>53</td>
</tr>
<tr>
<td>Self-care</td>
<td>44</td>
</tr>
<tr>
<td>Alternative therapy</td>
<td>44</td>
</tr>
<tr>
<td>Usefulness of information from non-health professionals</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
</tr>
<tr>
<td>Overall access to health information on breast cancer</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>15</td>
</tr>
<tr>
<td>Good</td>
<td>107</td>
</tr>
<tr>
<td>Very good</td>
<td>68</td>
</tr>
<tr>
<td>Excellent</td>
<td>15</td>
</tr>
</tbody>
</table>

<sup>1</sup> Percentage does not add up to 100 due to multiple responses.
Health literacy had an indirect influence on quality of life through both depression and anxiety after controlling for access to information. As can be seen in Fig. 1, increased health literacy predicted decreased depression ($b = -0.349$, $t = -3.498$, $p < .001$) and anxiety ($b = -0.328$, $t = -3.394$, $p < .001$). Higher depression ($b = -0.358$, $t = -9.929$, $p < .001$) and anxiety levels ($b = -1.155$, $t = -9.877$, $p < .001$) predicted decreased quality of life. A percentile bootstrap confidence interval for the indirect effect through depression ($b = 1.250$) based on 10,000 bootstrap samples was entirely above zero (.700–1.878) and the indirect effect through anxiety ($b = 0.379$) based on 10,000 bootstrap samples was entirely above zero (.120–.703). There was evidence for a direct negative influence of health literacy on quality of life ($b = -0.631$, $t = -2.027$, $p < .05$).

4. Discussion and conclusion

4.1. Access to information by women living with breast cancer

It was observed that health workers (doctors and nurses), television and radio were the main sources of information about breast cancer among the women. Most of the women were satisfied with the amount and quality of information provided by healthcare professionals and also reported that their concerns were adequately addressed. A third of the women reported seeking information from non-health professionals which were mainly concerned with treatment, alternative therapy and self-care. The majority of the women who sought information from non-health professionals found the information they received as useful. The majority of the women living with breast cancer rated their overall access to information on breast cancer as good. This finding is consistent with previous studies that reported personal doctors, oncologists, family and friends, mass media as the main sources of health information among cancer patients [2,12,44]. This result also corroborates the findings from a systematic review and empirical research on information sources among cancer patients which found that the most frequent information source utilized was health professionals [3,4].

Since healthcare professionals play major roles in the lives of women living with breast cancer, it is not surprising that healthcare professionals were the major source of information as personal communication with some healthcare professionals revealed that breast cancer patients are mostly provided with verbal information as the majority of them have low literacy levels. However, the use of television and radio as the second and third most utilized sources of information about breast cancer in this study, contradicts a recent study which found both radio and television to be the least used sources of information on breast cancer [4]. These could be due to differences in socio-demographics as some evidence suggests that the preference for health information sources differed for cancer patients according to some personal characteristics such as age, sex, race and level of education [7,45,46]. That is, relatively younger patients and those who are highly educated may rely on information from new media including the Internet whereas older patients with little or no formal education may rely on television and radio as their key alternative sources of information.

One significant finding in this study is that a third of all the women sampled reported to have sought information from non-health professionals pertaining to treatment, alternative therapy and self-care. This percentage of patients seeking information from sources other than health professionals, may suggest unmet health
information needs and therefore, would explore other avenues for information about their illness [1,47]. It is also possible that their health care providers do not readily provide this kind of information, and they might not easily ask due to the existence of power differentials. The key challenge in patients seeking information from non-health professionals is the credibility of the information provided by these non-health professional sources. The emphasis on treatment and alternative therapy by the patients as the main reasons for seeking information from non-health professional sources may likely be due to their non-belief in the medical treatment or that they feel the treatment is not effective and therefore seek better treatment. This also calls into question the quality of information provided by non-health professionals which a critical national policy issue. These findings could also be related to the kind of side-effects of the medical treatment and as such, people with lower levels of health literacy might not understand the negative side effects and possibly do not “make sense of” when they expect to become better. Thus, providing health information to women living with breast cancer cannot be underestimated as evidence suggests that cancer patients rely extensively on alternative sources for health information [3,11].

4.2. Access to health information and health outcomes

The findings showed that increased access to health information enhanced the chances of better health outcomes such as decreased depression and anxiety which in turn result in improved quality of life among women living with breast cancer. The findings regarding the impact of access to healthcare information on depression, anxiety and quality of life could be attributed to uncertainties that characterize patients’ perceptions about treatment outcomes and prognosis. Thus, increased access to health information may serve to alleviate the levels of depression and anxiety associated with living with breast cancer which in turn result in improved quality of life. Even though one would expect that in some cases of factual information about negative treatment outcomes may heighten the levels of anxiety and depression among the patients, this was not the case found in this study.

These findings highlight the importance of information needs of breast cancer patients as evidence suggests that access to health information leads to better mental and physical health outcomes [15,16]. In this study, access to health information did not have any significant direct influence on the quality of life among the participants. This finding is consistent with previous studies which did not find any significant direct influence of access to health information on the quality of life among cancer patients [19]. However, the results showed indirect of access to information on quality of life through short term health outcomes such as decreased depression and anxiety.

Access to health information plays an important role in the lives of persons living with chronic medical conditions as the uncertainties and challenges associated with the medical treatments may be lessened with accurate and relevant information from both health and non-health professional sources. This becomes even more importance taking into cognizance the multiple medical treatments being received by the women sampled in this study. Therefore, breast cancer patients access to information medical treatment in terms of prognosis and alternative therapy could help lessen their psychological burdens including depression and anxiety [12,15].

4.3. Health literacy and health-related quality of life

The results indicating that health literacy led to decreased depression and anxiety levels which result in improved quality of life are congruent with previous works which found significant associations between higher health literacy and improved health outcomes such as health-related quality of life [34,48]. Evidence has linked limited or poor health literacy to several negative short and long term health outcomes including increased depression and anxiety levels, and poor quality of life [24,32–34]. These findings could be due to the demanding nature of the treatment process which requires individuals to have information about the potential benefits and possible side effects. Those with limited health literacy may find it difficult in obtaining the needed information which could heighten their depression and anxiety levels.

Surprisingly, after controlling for other study variables such as access to information, depression and anxiety, health literacy had a significant direct but weak negative influence on the quality of life among the participants. This suggests that higher health literacy is associated with decreased quality of life. This could be due to the fact that health literacy alone may not be enough in influencing patients’ wellbeing as more information from different sources which is one of the key attributes of health literacy could be detrimental to the quality of life of the women. This is because some negative information about breast cancer on prognosis and complications of the medical treatments could negatively impact on the wellbeing of the women. This contradicts what was found in others studies that health literacy is associated with improved health outcomes [24–26]. It is worth noting that some cross-sectional studies did not find evidence of a direct influence of health literacy on health-related quality of life among cancer patients [33,34]. Thus, the possible mechanisms of the impact of health literacy on health outcomes of women living with breast cancer should be the focus of future studies.

4.4. Limitations

This study has some limitations which need to be considered in the interpretation and application of these results. The use of cross-sectional design could not account for other transient factors that may have impacted the responses of the participants. It is also worth noting that no causal relations can be assumed between the study variables. Since the healthcare staff do not provide participants with leaflets containing information about their condition and its management, the health literacy scale used did not include the functional aspect (patients’ ability to read hospital leaflets), which needs to be taken into account. Despite these limitations, this study provides evidence on information seeking patterns, the possible mechanisms that could explain the links between access to health information, health literacy and quality of life which have been sparsely researched.

4.5. Practice implications

The findings of this study have some practical implications. First, the use of various information sources by the women living with breast cancer implies that healthcare providers should constantly assess patients’ knowledge to be sure that the correct and relevant information are being processed. This could also help in identifying patients who have limited health literacy as higher literacy in this study correlated positively with increased health-related quality of life domains. Since access to information has been found to have both direct and indirect effects on the quality of life among the participants, the information needs of the patients should be a priority area in oncology practice especially to patients who desire more information about their condition. Secondly, healthcare providers should encourage patients to ask questions and seek clarifications as these may help in reducing the level of depression and anxiety associated with diagnosis and treatment as well as treatment side effects. There is the need for timely
screening and care for common mental health problems such as depression and anxiety among women living with breast cancer as these present significant challenges to their quality of life.

4.6. Conclusion

The results from the study showed that women living with breast cancer resort to varied sources for information about their condition with the three most prominent ones being health workers (doctors and nurses), television and radio. However, the reliance on the television and radio suggests that there is the need to streamline the quality of information on breast cancer provided by these media outlets. It was also found that a substantial number of women utilize non-health professional sources of information regarding treatment and alternative therapy which suggests a need for improvement in the unmet information needs regarding treatment in general and health outcomes. The mechanisms through which access to health information and health literacy influenced quality of life among women living with breast cancer were through mental distress as well as depression and anxiety.

Conflicts of interest

None.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Authors’ contribution

NK, AMW and KOA conceptualized and designed the study. NK was responsible for the data collection and conducted the data analysis. NK drafted the manuscript and AMW and KOA revised the final manuscript.

Informed consent and patient details

We confirm that all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Acknowledgments

We would like to thank the hospital authorities for access and also the participants for agreeing to voluntarily participate in this study.

References