



The Importance of Culturally Relevant Breast Clinic Navigation in Improving Breast Cancer Care in Africa

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ABSTRACT

Objective: Cultural norms, community-specific cultural or religious beliefs, and resultant patient health-belief models are known to pose a significant but imperceptible barrier to breast cancer care. However, there is a paucity of data addressing the need for culturally relevant breast clinic navigation in the context of culturally diverse regions. Thus, this study aimed to assess the benefit of culturally similar breast clinic navigators in facilitating treatment adherence and improving overall care in patients.

Materials and Methods: This study was a retrospective qualitative study. It included breast cancer patients who attended our clinic from January, 2017 to December, 2017 and whose management plan included neoadjuvant chemotherapy. These patients were assigned culturally similar breast clinic navigators who counselled them from diagnosis, to treatment, to survivorship. Additionally, navigation concerns were grouped into the following: Navigating the neighbourhood, navigating hostile hospital environments, and navigating medical consultations.

Results: Through counselling sessions and regular telephone follow-up, breast clinic navigators were able to address navigation concerns, provide support for the patient as well as inform the multidisciplinary team (MDT) on the patient's thought process and potential barriers for care. Thus, treatment plans were personalised, resulting in improved, holistic care.

Conclusion: The role of culturally relevant patient navigators within the MDT is not well-described in the current literature. However, this role is useful where a gap exists between medical professionals and patients from varied backgrounds. Thus, navigators from the same/similar backgrounds help improve the healthcare worker's understanding of the patient's thought process, ensuring good quality and holistic breast cancer care.

Keywords: Breast cancer; navigation; patient care; Africa

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Key Points

- Cultural barriers to care are significant but intangible barriers to breast cancer care.
- Healthcare workers must accept belief in non-biomedical models of health.
- In turn, patient cooperation is important in their own medical care.
- Navigators can help bridge the gap between the patient, the community, and the specialist.
- Thus, culturally relevant navigation improves patient adherence and overall patient care.

Introduction

Geographical Context

The Helen Joseph Breast Care Clinic (HJBCC), based in a public hospital in Johannesburg, South Africa, has been operating as a multidisciplinary unit since 2000. Treatment is provided for patients who do not have health insurance, which accounts for approximately 84% of the population (1). Patients are means-assessed and 60% of patients have a consultation and in-patient management for free or for less than US\$4.

The clinic manages between 500–700 patients each month, with approximately 350 new cancer diagnoses per year. The ethnic mix of patients reflects the Johannesburg urban population with 65% black, 17% white, 11% coloured/mixed-race and 7% Asian (2, 3). Locally advanced disease accounts for the majority of the unit's breast cancer diagnoses (62%). Referral to neoadjuvant chemotherapy prior to breast surgery (with or without reconstruction) and then radiation, is the typical treatment pathway.

The clinic also raises awareness of the importance of breast health through media and government initiatives. Education and training of healthcare professionals is provided in Johannesburg, Gauteng province, and also other African countries. The education of healthcare providers includes dialogue with traditional healers in the local community, thus promoting collaborative working relationships.

Breast clinic navigators are breast cancer survivors from different cultural backgrounds, ages and racial groups who function as clinical coordinators and counsellors. This promotes adherence to treatment and survivorship programs. Navigators translate medical systems and aid patients in traversing the multi-disciplinary practice of healthcare which involves different hospitals, doctors, and treatment plans. Navigators in the Breast Clinic also guide patients from diagnosis and through treatment by providing support from initial diagnosis through to survivorship. Additionally, navigation is both vertical (from patient to doctor) and horizontal (along different medical pathways), as personalised cancer treatment is offered via the multidisciplinary team (MDT).

Breast clinic navigators also work within their own communities whilst sharing insights into a patient's health-belief system and their shared cultural understanding with the MDT. They have, therefore, provided awareness of numerous unseen barriers which compromise patient care. This spans issues of failed clinician communication to fears and logistical concerns around hospital environments. Hence, navigator involvement is crucial in breast cancer care as advocating for access to treatment at different geographical locations whilst negotiating diverse health belief models requires a unique and specific skill set.

Background

The benefit of a breast clinic navigator in a high-resource setting is well understood (4). However, the use of navigation in countries with minimal screening or health awareness initiatives, different cultural backgrounds, and barriers to access of quality care has not been adequately researched to date. In fact, there is a paucity of published data on navigating systems that require communication across different languages and different cultural backgrounds (5). Moreover, although a patient's health-belief model and cultural context may create significant barriers to healthcare, there are few studies addressing

how the lack of culturally relevant breast clinic navigation may result in an equally important but less tangible barriers to breast cancer care (6).

Navigators in the HJBCC are from patient-specific communities. They highlight obstacles experienced by the patient, thereby aiding clinicians to adapt treatment pathways whilst addressing barriers of culturally based health beliefs. To the best of our knowledge, there are three identifiable cross-cultural barriers to care. These include, 1) inadequate communication due to language barriers, 2) delays in accepting treatment suggestions due to differing beliefs in disease and healing that may result from conflict between traditional medicine, cultural belief, and conventional medicine as well as, 3) rejection of the biomedical model due to patient mistrust or failures in communication and understanding between the healthcare professional and the patient. Thus, breast clinic navigators should be well-versed in both the clinical nuances of care as well as the cultural background of the patients. This is to facilitate a better dialogue between the healthcare providers, the surrounding community, and the individual patients; thereby, enhancing adherence to prescribed treatment regimens and improving overall care. Therefore, the aim of this study was to assess the benefits of culturally similar breast clinic navigators in facilitating treatment adherence and improving overall care in patients. The focus was on community-specific cultural and religious beliefs as well as patient health-belief models.

Materials and Methods

Study Design

The study was a retrospective, qualitative observational analysis of breast cancer patients who attended the HJBCC. Data pertaining to the benefits of breast health navigators in understanding a patient's cultural context were collected through observation of current practices at the HJBCC. Patients were assigned culturally similar clinic navigators upon their breast cancer diagnosis. Following diagnosis, patients answered seven questions as per a template already provided to the clinic navigators, namely:

1. What has the doctor told you?
2. Did you understand what the doctor told you?
3. Did you expect this diagnosis?
4. How are you feeling about your diagnosis?
5. Do you have a family history of cancer?
6. What is your biggest concern?
7. Are you on any chronic medication?

These were administered as part of the first navigator counselling session. Following these questions and discussion, there was a focus on the patient's perception of their disease, health-seeking behaviours, family support and dynamics as well as their counselling experience with a navigator and doctor. Navigators also consolidated what breast cancer is, the type of breast cancer that the patient has, the next step of treatment and potential side effects. Notable, unique, and community-specific psychosocial and contextual issues were then recorded and collated upon consultation for the MDT's knowledge

and/or intervention. This was to ensure an individualised and complete understanding as possible for both the patient and the navigator as well as to ensure effective transfer of medical and logistic information from the clinician to the patient and vice versa.

Study Population

A total of 300 patients were included in this study. They were seen by three breast clinic navigators of different cultural identities and ages. The study comprised 178 (59.3%) patients who self-identified as Black, 86 (28.7%) patients who self-identified as White, 17 (6%) patients who self-identified as Coloured/Mixed-Race, and 19 (6%) self-identified Indian/Asian patients.

Inclusion Criteria

All newly diagnosed breast cancer patients seen at the HJBCC from January, 2017 to December, 2017 whose management plan included neoadjuvant chemotherapy were included.

Exclusion Criteria

Patients who received any treatment at other facilities were excluded. Patients diagnosed with breast cancer before the study start-period were also excluded.

Navigator Selection and Training

Navigators are individuals who have previously had breast cancer. They were recruited through the Breast Health Foundation in Johannesburg, South Africa. Candidates go through a rigorous training process, completing both a clinical breast cancer course and a lifeline-counselling course before being selected as full-time clinic navigators. Once selected, they work within their communities of origin or are assigned patients from culturally similar backgrounds.

Culturally Relevant Navigation

Newly diagnosed breast cancer patients were assigned culturally similar clinic navigators upon discussion with the MDT. Patients were assigned by virtue of their race (Black/White/Mixed/Asian), language preference or cultural background. Hence, patients were able to discuss their fears and concerns with their navigators as well as address their culturally based beliefs about their illnesses. Navigators then relayed pertinent information to the MDT and highlighted any obstacles to patient care in meetings. Moreover, after a treatment plan was decided upon, the patient was contacted on a monthly basis, by telephone, to assess their concerns (logistical and medical) being experienced so as to facilitate adherence to their treatment.

Low-resource environments are those in which healthcare resources are limited. In South Africa, the public health sector is understaffed and overworked (1). Resource limitation is further aggravated by the unequal distribution in the “per capita expenditure” between South Africa’s public and private health sectors. Two-thirds of the GDP allocated to health (approximately 5.2% of the total GDP) is assigned to the private sector with the per capita expenditure on healthcare ranging from US\$140 in the public sector to US\$1,400 in the private sector (1). Conceptualising issues into three specific navigational barriers centred around cultural beliefs has contributed to a successful patient care model for such environments to ensure better patient adherence, and therefore, better patient outcomes. Thus, navigational concerns were grouped into the following:

1. Navigating the neighbourhood
2. Navigating hospital environments
3. Navigating medical consultations.

Navigating the neighbourhood

Perceptions of breast cancer have changed over the last 30 years, with the realisation that it occurs in any race, age, or culture. Awareness in South Africa has involved both successful and failed community education projects, mainly led by media-directed public health campaigns, and breast cancer advocacy and support groups (7). Thus, navigators were tasked with determining the reasons behind some projects’ failures and how to make breast health awareness more relatable for people living in their surrounding communities.

Navigating hostile hospital environments

Insights into the perception of a “hostile hospital environment” need to be re-addressed in both patients and communities. The financial and social cost associated with breast cancer treatment needed to be better understood and addressed in order to improve patient care.

Navigating medical consultations

Misinformation around treatments or perceived complications around clinical modalities of care may not always be addressed by the treating physician. Additionally, the patient’s cultural and/or spiritual beliefs about their illness may not be adequately engaged with. Thus, the navigator’s role after the medical consultation was to address any treatment hesitation that may have stemmed from a lack of information as well as help accommodate the patient’s cultural or spiritual norms within their breast cancer management.

Results

Unique/Community-specific Cultural Barriers Identified

- The concept of disease as a familial issue. Thus, the conversation surrounding diagnosis and treatment must be directed at the familial patriarch/matriarch as is noted in predominantly Indian/Asian as well as some Black communities.
- The concept of disease as a spiritual phenomenon which requires ancestral/spiritual intervention as seen in some Black or non-race specific religious communities.

Navigating the Divide of Breast Healthcare

1. Navigating the neighbourhood

Listening to patient navigators from the community who highlighted the reasons for failure of these projects and redirected information based on local cultural belief systems resulted in an increase in patient attendance to treatment centres. Initial problems such as the diversity of languages spoken, poor literacy in English, and an inherent suspicion of accepting advice from women of a different cultural background were corrected by the involvement of the navigator, through provision of personalised information and training within the community. This training included understanding preconceptions and beliefs around the cause of cancer, which were resulting in symptomatic women not accessing care.

2. Navigating hostile hospital environments

The role of the breast care navigator in this regard was critical, as he or she interfaced with the patient, the community, and medical personnel working in regional clinics. The above-mentioned barriers were, therefore, addressed to ensure personalized patient care.

The navigator also provided a more successful conduit to answering questions about hospital treatment misconceptions such as hair growth after chemotherapy, or abandonment post-mastectomy. Additionally, navigators discussed non-surgical management options with patients, including a trial of endocrine therapy in endocrine-sensitive breast cancer which could allow for time to deal with medical fears of treatment or perceived imminent death by both the patient and their family.

3. Navigating medical consultations

Breast clinic navigators ensured that patients were well-informed on both breast-conserving surgery and mastectomies. Moreover, navigators with similar belief structures to the patients could successfully support and aid newly diagnosed women in accepting an inclusive rather than exclusive approach to their treatment options. Thus, the role of the navigator in asking relevant questions about other treatment regimes, as well as in understanding a patient's thought processes around treatments, aided better compliance, and avoided late presentation of advanced disease due to alternative treatment seeking behaviour.

Lastly, phenomena that had an effect on help-seeking behaviour included a lack of knowledge about what a symptom means in addition to the fear of both management strategies and outcomes of the disease or the treatment process. There was also a sense of disconnect regarding formal health systems and a lack of confidence in such systems.

Discussion and Conclusion

Beliefs around breast cancer differ amongst different racial and cultural groups (8). While little has been studied on the beliefs of cancer in South Africa, studies into adherence of antiretroviral treatment for HIV/AIDS indicate some potential cultural barriers, which can also be extrapolated to cancer care (9). Cultural barriers to care are important albeit intangible barriers which if appropriately addressed could improve patient adherence and the overall experience from diagnosis to survivorship. Understanding the perceived cause of the disease, including concepts of curses and spiritual punishments (current and generational), could help explain reluctance to confront the disease. Additionally, misinformation may breed misconceptions about the disease and so it is necessary to address false or negative beliefs associated with conventional medical treatment as well (10, 11).

Generally, misinformation around treatments or perceived complications around clinical modalities of care may not always be addressed by the treating physician. Furthermore, accepting conventional breast cancer treatment poses more culturally specific dilemmas which may not be noticeable during the patient-doctor interaction. An example of such a dilemma, taken directly from this study, is that some cultures do not have a model of patient autonomy. Therefore, it is important to ascertain to whom news of diagnosis should be directed. This may be further complicated by distance and presence of the family patriarch/matriarch (decision-maker). However, the need for consent from the husband or family elders, who may not reside locally, delays treatment. Hence, travel to non-urban areas, with concomitant seeking of traditional healing advice or treatment,

may be necessary but is often perceived as favouring no treatment. The result is that the patient may default or be seen as a "defaulter" on the determined treatment plan. Thus, a culturally aware navigator was often required to visit the home, or to have repeated telephone follow-ups with the patient to ensure that this was not the case.

Moreover, patients with a belief in a higher power may often wish to embark on a trial of prayer. Medical practitioners are sometimes perceived to be spiritual sceptics and as not being able to understand the importance of faith in spiritual powers. Patients may also believe that seeking medical treatment is a sign of weakness in religious faith and an indication of doubt in the healing power of "God". This view may be further propagated by charismatic leaders encouraging patients to seek only religious healing, with fatalism in God's punishment taking priority over conventional care. Strong beliefs in chance or fatalism may, therefore, lead women to recognise the presence of the disease but be disinclined to remedy it (12).

A breast cancer diagnosis may also be seen as a part of a curse or disapproval of ancestral powers. Hence, the resultant cure cannot be found in a medical model but in appeasing the ancestors prior to seeking medical treatment. Navigators in our environment were able to bridge this divide between faith and medical management by virtue of their training and individual life-experience. In fact, navigators with similar belief structures as the patient, who have had breast cancer and likely wrestled with similar thought processes, could successfully support newly diagnosed women in accepting an inclusive rather than exclusive approach to treatment options.

Additionally, fear of breast cancer treatment is widely described (13, 14). Many studies have shown that concerns around the concept of a mastectomy are not a phenomenon unique to non-westernised cultures (14). However, these concerns are often managed insensitively by medical practitioners who have been blunted by the attitude of life over limb. Increasingly, breast-conserving surgery is offered in most specialist units either pre- or post-neoadjuvant chemotherapy and comes with obligatory radiation. However, women may be unaware of advances such as breast-conserving surgery and would, therefore, delay treatment because of the fear of mastectomy and lack of information provided by the doctor. Thus, breast clinic navigators are crucial in providing information and ensuring patients are well-informed about all treatment options available to them.

In addition to interpreting and explaining treatment misconceptions and fears to both the physicians and the patients, breast clinic navigators expedite access to multidisciplinary breast units. This is through their engagement with local primary healthcare professionals, which facilitates earlier diagnoses and detection of non-adherence to treatment. Furthermore, navigators not only work with patients in the hospital, but also visit women in the community. This allows them to share their experiences and wisdom as well as encourage co-operative community détente within the communities they are from or familiar with. As a result, these navigators can prove essential in improving the dialogue between the patient, the community, and the specialist.

Regrettably, access to breast cancer care may be limited by a patient's financial constraints (10, 15). Accessing chemotherapy facilities and hospital admissions for breast cancer surgery when salaries or pensions need to be collected would often result in a perceived non-arrival for care. Lack of easily accessible transport would also prevent patients from attending clinics, receiving medication (endocrine therapy) and/or daily radiation sessions. Moreover, monthly payments of repeat

medication prescription collections would further impair adherence in financially burdened patients. Thus, navigators engaged with the patients about their finances as the patients can feel comfortable to relay such financial issues to someone whom they feel would understand them. In turn, navigators conveyed these issues to the MDT so that treatment can be individualised and tailored to the patient's social context.

Therefore, one of the primary solutions to overcoming cultural barriers to care is knowledge (16). There is a duality of awareness which must take place both with the healthcare professional and the patient. Healthcare professionals must accept belief in non-biomedical models of health, and work with the patients (via navigators) to find acceptable solutions and treatment plans (17). Conversely, patients and the community can be educated by navigators about the importance of co-operative medical care. As pointed out by Meara et al. (18) in the Lancet Commission on global health: "Although healthcare has improved in the last 25 years, the development is not uniform, with the most noticeable deficiencies in the system seen in the developing world" (18). Part of the improvement of global healthcare can be achieved through navigation-based education which encompasses a biopsychosocial approach to patient care. That is, successful patient navigation involves the provision of individualised healthcare by understanding the community background of a patient, including the racial, cultural, and educational influences which affect access to healthcare and adherence to treatment. Such understanding is optimised when a breast clinic navigator is chosen from a similar racial and/or cultural background as the patient population of the community in which they operate.

Cultural barriers to healthcare, and specifically, to breast cancer care exist. These barriers are intangible but should be acknowledged to ensure well-rounded patient care from diagnosis to survivorship. Furthermore, the interplay between medicine, culture and beliefs about breast cancer diagnoses underline the importance of holistic, culturally aware patient navigators in the MDT. These navigators should have diverse medical and cultural areas of expertise, ensuring optimal communication between the treating physicians, the patients, their families as well as the surrounding communities. Furthermore, understanding the possible disparities between culture, patient health-beliefs and conventional medical practices promotes adherence to treatment and, therefore, improves the efficacy of care. Currently, the formal incorporation of culturally relevant patient navigators within the MDT is not routinely described. However, this role is useful where a gap exists between medical professionals and patients from varied backgrounds. Learning from this in our shrinking global village, where access to information may encourage divergence from current medical "gold standards", is also essential. Thus, further research into the role of culturally relevant patient navigators in breast cancer care in Africa, and beyond, is also necessary as navigators, today, play a vital role in the daily practice of breast care units. More so, navigators who are culturally similar to the patients whom they counsel help improve the healthcare worker's understanding of the patient's thought process and thereby help improve overall patient care.

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Authorship Contributions

Surgical and Medical Practices: C.A.B.; Concept: C.A.B., D.V.L.; Design: C.A.B., D.V.L.; Data Collection or Processing: C.A.B.; Analysis or Interpretation: C.A.B., D.V.L.; Literature Search: C.A.B., C.P.T.M.; Writing: C.A.B., C.P.T.M., D.V.L., J.M.

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