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Female breast cancer as taboo: Cultural factors and awareness amongst patients and their families in the Philippines

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Abstract

Statistical information from cancer studies show that the Philippines has the highest incidence rate of breast cancer in Asia. Efforts on creating awareness are being spearheaded by the country's health department, local governments, and cancer-interest organizations. Despite these, discussions on the issue remain a forbidden topic among many Filipinos, particularly the patients and their families themselves. This study aims to know the central discourses behind the prevailing treatment of Filipinos on female breast cancer as taboo and the correlation to the slow development of awareness on the illness. A quality circle was conducted on three middle-aged women from General Santos City, southern Philippines. All of the respondents were breast cancer survivors. A discourse analysis on the data figured that there are two central and interconnected discourses hindering the awareness and acceptance of breast cancer: (i) fear and denial due to financial instability, and (ii) folk belief. The researchers suggest that instead of coursing breast cancer treatment budget through the Philippine government's health insurance provider, it should be directly allocated to the country's health services program. They concluded that beyond creating awareness, it is with the accessibility of treatment that the Filipino people will be liberated from the prevailing central discourses on breast and any type of cancer.

Keywords: breast cancer, discourse analysis, Filipino culture, patient, Philippines, public health

Introduction

Among Asian countries, the Philippines has the highest incidence rate and also has one of the highest mortality rates for female breast cancer (Youlden et al., 2014), with up to one-third of women having family history of the said illness (Liede et al., 2003). Additionally, the Philippines also has the highest age-adjusted rate in the Asia-Pacific region with 0.99 per 100,000 men (Ly et al., 2013). While incidence rates are almost twice as high in developed countries, there is a disparity of 8% to 15% in the mortality rates with the developing (more specifically, low income) countries as only less than 25% of their population have access to cancer treatment such as radiotherapy (International Atomic Energy Agency as cited in Torre, et al., 2015).

The Clinical Epidemiology Unit of the University of the Philippines, which took part in the Collaborative Group on Hormonal Factors in Breast Cancer, identified the following risk factors that may lead to female breast cancer: (i) women who are currently using or have used combined oral contraceptives in the last 10 years; and, (ii) post-menopausal women while taking hormone replacement therapy or in the 5 years after stopping use. The study also found out that the significant risk factors of Filipino breast cancer cases were found on people who lived longest in rural areas, who had lower than high school education, had a history of benign breast disease, infertility, and were in the age greater than 35 during first pregnancy. People who belong to the higher socioeconomic strata, however, has shown no cancer risks (Ngelangel & Wang, 2002).

Breast Cancer Prevention Programs in the Philippines

The Philippine Department of Health (DOH) established the Breast Cancer Control Program (BCCP) as its national anti-breast cancer program that does awareness through public information and health education, integrating case finding and treatment in the community health structure, and has been equipped to control breast cancer in a sustained manner. It saw the importance of having an annual clinical breast examination and a monthly breast selfexamination (BSE) as mammography is not easily available in many hospitals in the country, and it is also not affordable. In a 1989 study of that surveyed Metro Manila's women's health and childcare, only 37% of women received a formal breast examination from a physician (Ngelangel et al., 1992). Sixty-seven percent of the respondents knew the benefits of doing a BSE, but only 54% has done it. Only 27% were practicing it still that time. A 1993 study on the determinants of late-stage diagnoses of Filipino breast cancer has shown that economic factors, non-awareness of the gravity of breast cancer, and fear of being diagnosed with cancer were the three main reasons for late diagnosis. The study was later on affirmed in a 1997 study done by the DOH and the World Health Organization in Metro Manila. It indicated that 79.1% of women who were found to have breast masses did not comply with the set consultation referrals and reevaluation. Reasons said were fear, no money for transport/treatment/medical expenses, indifference, no-time, non-awareness of gravity of the disease, and spiritual fatalistic attitudes (Ngelangel & Wang, 2002).

According to the Philippine Cancer Society (PCS), while awareness campaigns work in high-income countries, 80% of Filipino families cannot afford to shell out money from their own pockets for basic medical care. Spending by people on medical care decreased from 3.4% in 2005 to 3.2% in 2007. The Philippine government only contributes 13% of the total health expenditure of the Filipinos. Despite efforts of the state health insurance provider PhilHealth in enrolling families belonging in the lower socioeconomic strata, these people remain uninsured and underinsured as they cannot afford to pay for the insurance premium. The country's strict regulations on medicine that could prevent cancer pain such as prescription morphine and strong opioids are blocking patients from having access of it. The PCS states, "These unbalanced regulations will not contribute anything significant in the war against illegal drugs, and hundreds of thousands of Filipinos will continue to suffer from unrelieved pain." Furthermore, they are saying that balanced policies and proper facilitation of these drugs can significantly help patients in their struggle against cancer (Laudico et al., 2014, pp.12-13).

Recently, a pilot project by the PCS integrating breast cancer detection and treatment in Metro Manila has been connected to a Patient Navigation System. It will help patients from financially unfortunate backgrounds to go through socioeconomic obstacles, which they consider as barriers, to detect breast cancer early and treat it immediately (Laudico et al., 2014, p. 14).

Common cancer treatment done in the Philippines

A study (Alinsug et al., 2002) documented the varying treatments that breast cancer patients commonly undergo in the Philippines in six major public and private hospitals. They found out that out of 223 patients, 95% of them complained that they felt a breast lump that is why they went to a medical doctor to seek information about their condition. Sixty-nine percent (69%) of the respondents underwent open biopsy, while 51% had frozen biopsy, a one-stage process that brings them en route to a breast cancer surgery. Forty-three patients in a public hospital underwent fine needle aspiration biopsy. The most common metastatic work-up done on the patients were chest radiograph and liver enzyme determination. Only 13 patients (29% of the respondents) underwent a preoperative mammogram. About 64% of the respondents were able to detect breast cancer at its early stage, 24.7% were diagnosed with locally advanced cancer, and 26% had terminal-level diagnosis already. Of those who were diagnosed with breast cancer at its early stage, 138 of them preferred modified radical mastectomy as a procedure. Forty-three patients who had been diagnosed with advance stage cancer also preferred the same procedure. Only two patients did breast conservation surgery. Morbidity rate was at 11.5%. Seroma, surgical site infection, and operative site hematoma were the most common complications that 79.2% of patients experienced. After surgery, 33.5% of the patients underwent chemotherapy, while only 23.4% of them only proceeded with radiotherapy and hormonal treatment.

Asian discourses on breast cancer

Psycho-oncologist Jimmie Holland said that culture plays a big role on how cancer is discussed, most especially on the truth about its diagnosis. Moreover, he emphasized that it can affect how patients and their families perceive the illness and its treatment, and how they cope with it (as cited in Benowitz, 1999).

The Asian population is receptive when talking about cancer. In a 1994 psychooncology survey of bereaved family members in Japan found that only 20.2% of cancer patients were told of their true diagnosis (Uchitomi, 1999). There is a strong denial and cultural clout amongst Japanese and Korean breast cancer patients. However, the newer generations who were more exposed to Western culture and seeing Japanese public figures announcing their terminal health conditions made them more open in discussing cancer (Benowitz, 1999).

Aside from the costs pertaining to cancer treatment, Singaporean women think that they will be unable to understand and act upon the information if they knew they had breast cancer. Sixty-three percent of female Singaporean breast cancer patients thought that attending sessions to manage their treatment will not make a difference as they already 'had cancer.' 'I do not like to hear bad news' was a phrase associated as a significant potential barrier among Singaporean breast cancer women (Chin et al., 2005).

In Taiwan, people emphasize their strong family ties. Just like predominantly Chinese Singapore, Taiwanese society treats the topic of death as a taboo. A typical Chinese family would protect their family from any kind of harm and instability. To maintain family harmony, family members would not tell the cancer prognosis of their patient. This traditional cultural principle of nonmaleficence among the Chinese prevent truth telling to patients (Lai, 2006).

In developing and developed countries such as Malaysia, Korea, China, and Iran, women seek alternative and Eastern medicine, missing the critical treatment needed for the early stages of breast cancer. By the time they visit a specialized physician, their breast cancer is already in an advanced stage, succumbing to the illness. Fear, doubt, and denial are

seen in patients who are less-educated and highly educated (Parsa et al., 2006). In the island of Pangkor, Malaysia, 64 respondents in a study revealed that despite their community's consciousness and awareness regarding their health, they only pursued treatment for chronic diseases, including cancer, when they already diagnosed (Rose & Lyndon, 2014). Cultural factors such as inability to act without the husband's permission, fear of the giving stigma to the family (especially the daughters), and fear of being excluded from society were also barriers on breast cancer screening (Smith et al. as cited in Parsa et al., 2006).

Religion in India, meanwhile, does not affect any cancer risks of patients - peoples' lifestyle does (Agarwal & Ramakant, 2008). Breast cancer incidence rates in Mumbai are found highest in Parsis and Christians. The Parsi community is known for their westernized lifestyle, consanguineous marriages, and late age of marriage and childbirth. In Chennai, the highest rates were found in Christians, followed by Hindus and Muslims. Lastly, the lowest rates were found in Jains and Buddhists.

Yew and Noor (2015) identified the distinction between complementary and alternative medicine and medical anthropology by doing participant observations and indepth interviews on ten Malaysian Chinese cancer women survivors. They found out that survivors' preference for complementary and alternative medicine use during cancer diagnosis was found to be influenced by their values, beliefs, and practices with respect to five distinct areas, namely, widespread acceptance of a combined Western and Eastern treatment, traditional Chinese philosophy, existential or life threatening situations, social relationships, and positive influences of global networks.

Methods

Small group research was utilized to conduct this study. In social psychology, particularly in the fields of stereotyping and intergroup relations, "small groups" are described as a cluster of people sharing social characteristics such as ethnicity and gender. However, Campbell and Heider (cited in Kerr & Scott Tindale, 2014, p. 188) defined it as "a collective of persons whose history of shared fate, common purpose, and interaction has led to the perception, by participants and outsiders alike, that this collective is a social unit."

One of the methods used in collecting data in small group research is through quality circles (QCs). Hutchins (1985 cited in Kerr and Scott Tindale, 2014, p. 208) described QCs as "a group of between three to twelve people who do the same or similar work, voluntarily meeting together regularly...and trained to identify, analyze, and solve some problems in their work, presenting solutions to management and, where possible, implementing solutions themselves." Its functions as a research methodology include collecting significant data through face-to-face meetings and brainstorming, scrutinizing problems, and producing recommendations (Kerr & Scott Tindale, 2014, p. 209).

While quality circles are mainly used in business and management settings, the researchers found it necessary as methodology as the respondents of the study came from a breast cancer organization, fitting the definition of set by Hutchins.

Respondents

The respondents were members of the Breast Cancer Society of Southern Mindanao, an organization based in General Santos City, southern Philippines. There was an effort to know the respondents' age, educational attainment, general working fields, and the period of which they had breast cancer. All were informed of the purpose of the study that is to know the factors affecting the hindrance of awareness regarding breast cancer among Filipinos.

All three respondents were middle-aged women (42-58 years). Two were college graduates, while one had a master's degree. All participants were in the private sector (business, financial investments, teaching) during the study was done. However, one had experienced serving as a government official. The respondents battled breast cancer for 3-4 years. All were survivors.

Procedure

The quality circle was moderated by the co-author, a graduate student and researcher in the field of Philippine cultural studies. The two-hour session was audiotaped. The moderator asked questions in the Filipino language, and the respondents were allowed to answer in the Filipino, Cebuano, and English languages. The discussion was translated and transcribed in English for this study. Before the QC was conducted, a verbal consent was given by the respondents to the investigators in utilizing the data given. Anonymity of the respondents was also assured.

The study was conducted in a conference room of a local high school situated in the central area of General Santos City, southern Philippines. It was chosen as the location was convenient for respondents using both public and private transportation. The respondents referred to each other on a nickname basis. Refreshments were provided. An honorarium of 500 pesos was given at the end of the session, and the respondents were thanked for their participation.

A discussion guide was developed and used by the moderator than included the following questions: (i) What was your perception of cancer before you had breast cancer; (ii) What was your initial reaction when you found out that you had cancer; (iii) Was it hard for you to say it to your family, relatives, and friends; (iv) Did having breast cancer affect how people treated you; (v) Aside from having treatment in the hospital, did you consider to visit a folk healer or take alternative medicine; and, (vi) aside from the ones mentioned earlier, what could be the other relevant factors in hindering the awareness on breast cancer amongst Filipinos? Following the broad questions, follow-up questions were asked by the moderator to ensure that the ideas, attitudes, beliefs, and opinions of the respondents were fully discussed.

Data analysis

This study utilized discourse analysis in examining the language use in transcripts to identify the central themes of the discourses hindering the awareness on breast cancer amongst Filipinos. Phillips and Jorgensen (as cited in Onwuegbuzie et al., 2009) mentioned that it analyzes data in detail to "examine how…elements such as the society, community, institutions, experiences, and events emerge in discourse."

Results

The results were organized in six sections. Each section will contain the relevant segments of the respondents' answers on the questions asked in the discussion.

Point of view on cancer before breast cancer diagnosis

All the respondents thought of cancer as a deadly illness. One, however, was confident that it can be taken care of through treatment as the respondent had a family history of cancer survivors.

"Of course, cancer is known to be a deadly illness. But my family has a history of cancer patients who survived the illness" (R-1).

"Before I had breast cancer, I thought of it as a terminal illness leading to death" (R-2 and R-3).

Aside from the first participant who was aware of the possible treatments that can cure cancer, the other two participants had new views regarding the illness when they had treatment. They had positive outlooks in life after being declared as cancer-free individuals.

Initial reaction upon cancer diagnosis

The first thought that came into the mind of the respondents when they were diagnosed with breast cancer was the financial obligations that came in with the treatment.

"I am single. I thought I was going to lose all my fortune!" (R-1).

"My husband and I come from a working class background, and my children were still studying at that time. Where will my family get the money for the treatment?" (R-2)

"During that time, I got separated from my husband. I lost my job. I barely had enough to support my younger child. The eldest child was already a nurse, but his salary was only small. I really did not know what to do back then" (R-3)

This study, however, noted that the respondents, later on, started having positive outlooks when development in their treatment happened. A respondent's doctor's fee was waived, and all received support from their family and friends. They all treated the help on the treatment as "God's blessing."

Letting people know of the cancer diagnosis

Two respondents had a hard time letting people know about their illness as they were known to be very active in their work and fields. One freely accepted her diagnosis due to having prior medical knowledge and let the family know about it immediately.

"I am the eldest child. I am the leader of the pack. I am in the social scene of the city, and the people knew who I am. Everyone relied on me to give them strength. But when I was diagnosed [with breast cancer], I did not know where to get the strength that I needed. I already felt in the year 2013 that I had breast cancer, but it was only in 2015 that I went to the doctor to have it checked when there was already liquid that was coming out of my breast. It was only then that I told the situation to the people closest to me" (R-1)

"Most of my family, close relatives, and friends are in the field of medicine, that's why it was for me to tell them the diagnosis. My relative was a medical professional, and I let him to the talking to my family to calm them down" (R-2)

"I really had a hard time admitting to myself that I had the illness. I was known to be a really healthy person. I was also a workaholic. I knew that my friends and workmates would be really shocked if they knew I had breast cancer" (R-3)

People's treatment upon cancer diagnosis

All respondents agreed that cancer had a negative connotation on the people. Two respondents experienced receiving negative comments from some people. They, however, had the support of their family, relatives, and friends.

"Some said that maybe I got cancer because I ran away from home back then. Some commented that this was because I was a smoker. Basically, it was like they were saying that I experienced bad karma. Despite those comments, all my closest family members, relatives, and friends gave me all the support and strength that I needed during the treatment" (R-1)

"You really cannot escape that some people might think of your situation negatively knowing the perception of people on cancer. My family and friends were there to support me all the way" (R-2)

"I agree with P-2 that people really think negatively about cancer. It was during that period of my life that I knew who my true friends are. It was during that time that I knew who were the ones who genuinely loved, and were always there to be with me" (R-3)

The statement of P-3 was also agreed by the other two respondents.

Perceptions on folk healing and alternative medicine

Two respondents were certain that it was treatment with trained medical doctors in hospitals would help them cure their illness. One had to visit a folk healer first due to her financial situation, but later went to treatment with medical doctors.

"From the very beginning, I had my treatment with the doctor. My doctor was very good. The doctor even told me that I can eat anything I want in moderation. My treatment went really well. I think that there's nothing bad about faith healing. I tried visiting one when I was invited. I was already cancer-free at that time, but it was reassuring that someone said that you are already cured" (R-1)

"As I said earlier, most of my family and relatives are medical professionals. I subjected myself solely to the treatment done by medical doctors" (R-2)

"When I was diagnosed with breast cancer, I did not have enough money for the initial surgery needed. I first went to quack doctor just to see if I can really get healed. I was told that the quack doctor was blind. After all the things I bought for the rituals that was done, I found out that the quack doctor can actually see. That was the time when I thought that I committed a sin to my God. Believing in a quack doctor was against the teachings of my religion [Roman Catholicism]. I confessed about my sin. I proceeded with the proper treatment with the medical doctors. I gave an advice a friend of mine who was undergoing spiritual healing in the church to really push through with the surgery. But I remembered an Australian doctor saying that it was only the patient who can decide what they want to do. Despite my insistence to people to really push through with their surgeries, if they are not interested in it, most especially if they don't have the money for it, I can't force them to do it. It is their decision" (R-3)

In spite of undergoing proper cancer treatment from medical doctors, all respondents viewed their recovery from breast cancer as a "blessing from God."

Other factors hindering breast cancer awareness

This section contains the closing statements of the respondents on what they think are the factors hindering breast cancer awareness amongst Filipinos.

"People are having hard time to accept that it can happen to anybody at any time. It's not just breast cancer, but any type of cancer. If you found out that you have cancer at an early stage, have it treated immediately. Don't be like me because I waited for a miracle, and nothing happened. People should also accepted that cancer can be treated. Most people might be incapable financially, but if they are willing to undergo through the right sense of treatment, people will help to lead you to the right doctor who will give you the right medicine at the right price. It is also helpful if you are in the midst of people like us, it is also a healing process for one to tell their story. You will realize that all of you have something in common. My story is not a different from R-2, and R-3's story is not different from mine. We all have that shared experience" (R-1)

"I agree with everything R-1 just said. But I would just like to manifest that as a breast cancer survivor, I will not stop gathering the stories and experiences of other breast cancer patients to make everyone aware and motivated to have their illnesses checked" (R-2)

"From my experience, I can say that fear, lack of guts to face the illness, denial, pride, and the negative view on cancer that it is bad karma, are hindering people from awareness and acceptance. However, because of what happened to me, I had closer family ties, stronger foundations, and my husband and I even got back together. I had the chance to do outreach to help the people with breast cancer" (R-3).

It is relevant to note from the closing statements of the respondents that after their grueling experiences as breast cancer patients, all of them were consistent in mentioning the

relevance of reaching out to fellow breast cancer patients and survivors, sharing their stories, and creating awareness.

Discussion

Following the analysis of the discussion's transcript, the researchers identified the two central and interconnected discourses hindering breast cancer awareness amongst Filipinos: (i) fear and denial due to financial instability, and (ii) folk belief.

Fear and denial due to financial instability

All the respondents emphasized the financial burden that came in with the surgeries and treatment needed to cure breast cancer. As mentioned in the earlier study of the Philippine Cancer Society, 80% of Filipino families cannot afford to shell out money from their own pockets for medical expenses. The researchers see that the feeling of fear and being in denial of having breast cancer was brought by the incapability of paying for the treatment needed to cure breast cancer.

If the Philippine government will continue with its plans to privatize hospitals (IBON Foundation, 2016b), then it will further prevent people from accessing breast cancer treatment. As mentioned earlier, PhilHealth, the country's health insurance provider, is already too expensive for the Filipino masses. Putting the budget for cancer treatment in PhilHealth also prevents people from having access to it. Moreover, according to the recent data, only 11.5% of total health expenditures are paid, and only 50% of the indigent claimants are covered by the PhilHealth insurance (IBON Foundation, 2016a). If the budget is directly coursed through the health services, then the Filipino people will have greater access to cancer treatment.

Folk belief

The Filipino discourses on folk beliefs such as bad karma and visiting quack doctors are interconnected with the discourse on fear and denial due to financial instability. In section 4.5 of this study, R-3 mentioned that the circumstance of being financially incapable made her visit a quack doctor.

Folk beliefs and spirituality is embedded in Filipino culture. The respondents, however, emphasized the need of an established medical professional specializing in cancer treatment. The researchers interpret the phrase "blessing from God," referring to their treatment, as health services being regarded as a privilege, rather than a universal human right.

Conclusion

Asian cultures play a role in discussing the cancer diagnosis of patients with their families, thus preventing them from having awareness of the illness. The Japanese (Uchitomi, 1999) and Singaporeans (Chin et al., 2005) had strong denials upon diagnosis. Taiwanese people want to maintain familial harmony, which is why they do not tell the cancer prognosis of their patient to not create chaos within the family (Lai, 2006). Despite having awareness about chronic illnesses, such as cancer, Malaysians only proceeded with the necessary treatments when they were already diagnosed (Rose & Lyndon, 2014). Several cultural

factors such as the inability to act without the husband's permission, fear of giving stigma to the family, and fear of being excluded from society became barriers for women who plan on having breast cancer screenings (Smith et al., as cited in Parsa et al., 2006). In Mumbai, India, meanwhile, people with westernized lifestyles, such as the Parsis and Christians, had the highest breast cancer incidence rates (Agarwal & Ramakant, 2008).

This study identified the central and interconnected discourses that hinder breast cancer awareness in the Philippines. In a small group discussion with breast cancer survivors from a cancer awareness organization, found that fear and denial due to financial instability and folk belief affect Filipinos' awareness about the illness. The authors posit that government budget for cancer treatment should be directly be appropriated through the country's health services system. Coursing the treatment's budget through the government insurance prevents patients from having access to treatment as they still have to pay a hefty premium. With the high costs of cancer treatment and insurance premiums, Filipinos visit quack doctors with the hopes of treating their illness. Beyond creating awareness, it is with the accessibility of treatment that the Filipino people will be liberated from the prevailing central discourses on breast and any type of cancer.

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