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#### ORIGINAL PAPER

# Impact of the Word "Cancer": a Pilot Study on Breast Cancer Patients from Pakistan

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**Abstract** Language holds great importance within clinical encounters, particularly when healthcare professionals are dealing with life-threatening diseases, such as cancer. This study is an attempt to explore the perceptions of women under treatment for breast cancer in Karachi, Pakistan, with respect to language employed by healthcare professionals for the disclosure of disease, and the impact that language used has on patients. Using exploratory qualitative methods consisting of 24 in-depth interviews with patients and one interview with a healthcare professional, this study reveals various nuances of language at play. We find that in Pakistani society, there is reluctance to use the word "cancer" during the disclosure of disease by healthcare professionals, family members and patients alike due to fear of imminent death and to retain hope in patients. Instead, colloquial language, such as "rasoli [mass]" and "this illness" is used to refer to the disease. The disease is disclosed with a deliberate attempt to avoid the use of the word "cancer", and often done in a series of steps rather than the diagnosis being spelt out bluntly, with the former practice generally preferred than the latter. Despite this manner of disclosure, patients remain aware that they are suffering from a disease. This has important implications for clinicians in Pakistan, where there are no standardized practices for breaking bad news, and where clinicians have to tailor their communication styles according to the type of patient, thus the onus rests on physicians to impart information in an empathetic manner to patients suffering from serious diseases.

**Keywords** Breast cancer · Physician-patient relationship · Pakistan · Language and cancer · Terminal disease disclosure

Published online: 26 September 2017

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#### Introduction

Historically, the existence of breast cancer can be traced back 3500 years, but it is only in the mid-nineteenth century that useful treatment options due to technological advancements became accessible to women (Cancer Research UK 2014). In 2013, breast cancer was stated to be the most common cause of death in woman in Pakistan. According to research, approximately 40,000 deaths occur due to this disease in Pakistan per year (Qasim 2013).

Medical education and training today lays emphasis on biological and technological advancements. However, an important lacuna in our education system in Pakistan is the lack of social sciences incorporated in the medical curriculum. The presence of social sciences would help bring in a more holistic approach towards treatment and healing. While it is important to scientifically consider the best medical option, it is equally important to realize that what may be the correct medical approach for one patient may not be the best choice for another. These differences are due to the social and ethical ramifications that are contextual to that patient alone, patients' understanding of the disease, her cultural values, and beliefs along with socioeconomic factors. The impact of the disease is not limited to the woman's body; it also impacts upon different facets of her life, like her support system, her interactions with her immediate family, and other important individuals in her life. In addition, reflecting on her psychological state, spirituality, and physical abilities of daily living cannot be excluded from her management (Van Wyk 2013).

These sociological, non-medical aspects of the disease have been explored largely in western literature, with some data from India, and also from South Asian women in the UK. The latter (Patel-Kerai et al. 2015, Singh-Carlson et al. 2013) essentially explore the views of Asian women and go beyond the science of cancer and talk about the cultural context and effective communication between patients and healthcare professionals. In addition, they look into the diverse impacts on the self and on others, such as fear, quiet acceptance, and intimate relationships. However, Asian perspectives remain sparsely represented in literature—and to the best of the authors' knowledge—this paper represents the first formal Pakistan-based analysis on this subject.

This paper presents research conducted on patients under treatment for breast cancer in the southern port city Karachi, the largest city in Pakistan and one of the largest worldwide. The aim of the study was to explore perceptions of these women about the language healthcare professionals employ to communicate with them during their treatment and the impact that the language used has on them. Therefore, the paper discusses the nuances of language, and the unique fashion in which the word cancer and its variations are utilized, affecting the manner in which the disease is disclosed.

# Methodology

We undertook an exploratory qualitative research design, based on interviews with patients diagnosed with breast cancer and with the primary physician responsible for treating these patients. As we have focused on breast cancer patients, it must be noted that their views may differ from those of patients diagnosed with other types of cancer.



This research is part of the thesis undertaken to fulfill the requirements for the Masters in Bioethics (MBE) programme by the first author from Centre of Biomedical Ethics and Culture (CBEC), Sindh Institute of Urology and Transplantation (SIUT) in Karachi, Pakistan.

The study was conducted in a private tertiary care hospital in Karachi during 2011. This institution was primarily selected due to convenience in accessing the outpatient clinic and because it was a hospital with a specified breast unit and a high turnover of patients. Prior to the conduct of the study, ethical approval was sought from the Ethical Review Committees (ERCs) of both SIUT and the tertiary care hospital. The ethical approval from SIUT was received on the 17th September 2010 and the one from the tertiary care hospital was received on the 24th November 2010, with reference App # 0018-2010 LNH–ERC. Data collection was carried out from January to March 2011.

All adult female patients who had been diagnosed with breast cancer within the last 3 months were recruited. Thus, they were either receiving chemotherapy prior to surgery, or had just been operated on and were under postoperative follow-up. The period was chosen so that an initial vulnerable phase of being newly diagnosed with cancer had passed, but that perception of the events had not faded yet. The patients were recruited with the help of the attending nurse running the afternoon breast cancer clinic on Mondays, a time convenient for the author, who collected the data.

The patients were explained the purpose of the study, and written informed consent was obtained from all participants. The interviewees were ensured that their participation was entirely voluntary, and refusal to participate would not affect their treatment in any fashion whatsoever. All patients who were approached except one (due to time constraints) agreed to be a part of the study.

The interviews were conducted in both English and Urdu, the national language of Pakistan. However, one participant could not communicate in either language, so her daughter was asked to interpret. The interviews were carried out using a semi-structured questionnaire, containing a series of open-ended questions, exploring the social impact of the disease including the process of diagnosis of disease, the manner in which the information regarding the disease was communicated and the number of people involved during the process of diagnosis and management of the disease. The questionnaire also included questions that sought to understand the patient's perception of her overall experience of diagnosis and treatment by her physician and the medical team. The questionnaire was initially drawn up in English, and then translated in Urdu by the first author as she is fluent in both languages.

Although the interview targeted patients specifically, it was noticed that they seemed more comfortable with having their accompanying family members or neighbors in the room, which was therefore allowed, keeping in consideration Pakistani cultural context and also on the understanding that it provided patients a sense of security. This further gave strength to data collection because the caregivers provided their own viewpoints, which reinforced what the patient also had said. At least two interviews were conducted during each visit to the clinic. In order to ensure the privacy of the respondents, interviews were conducted in a separate room in the outpatient clinic.

Each interview took about 30 to 40 min. All the interviews were recorded on a dictaphone. Data collection continued until thematic saturation of the data was reached and therefore, the total number of interviews was 24. Another considerably smaller arm of the study also included an interview with the primary treating physician, based on a



similar format as that of the patient interviews. The physician's perceptions of different styles of communications employed with patients were also explored.

The first author transcribed the interviews verbatim and then read each transcript to ensure congruence in data. Data analysis was largely thematic, conducted by both authors, utilizing selective coding method. Any emerging categories were coded in a selective manner, thus leading to a formation of themes that consisted of groups of codes. The first author analyzed most of the data, as part of her Master's thesis, thus author bias may have been introduced. However, we have attempted to remediate this through mutual discussion between the two authors and also through triangulation based on literature from other countries on the same subject.

# Findings and Discussion

All study participants were adult females. Twenty-three females were married. Thirteen participants were in the age range from 30 to 50 years, ten participants in the age range from 51 to 70 years, whereas the unmarried participant was relatively young.

Although the interviews revealed overlapping themes, the paper focuses upon the language employed during treatment of breast cancer by healthcare professionals, and the reasons why certain words were utilized, as opposed to others, showing certain nuances of language at play. It also explores the way language has an important role within the domain of physician-patient communication, particularly with respect to disclosure of diagnosis.

## **Nuances of Language During Breast Cancer Treatment**

The study revealed that during the process of treatment, breast cancer as a disease is referred to with different names by patients, family members and physicians alike in the Pakistani society. There was also a deliberate attempt to avoid the use of the word "cancer" during the treatment process for different reasons.

## Use of Colloquial Language

The use of language and its descriptive nature has always been distinctive to cultures. Often, colloquial language and metaphors capture meaning where formal terms might fail. The "meaning" of words and what they stand for has significance depending on situation, time and context.

In clinical encounters and outside within Pakistan, alternative words were employed to refer to breast cancer, including "beemari" [illness], "rasoli" [a common word in Urdu referring to mass], "yeh cheez" [this thing], "khatarnak beemari" [dangerous illness], and "maraaz" [disease]. These words although generic when used in relation with respect to treatment always implied cancer.

An important aspect highlighted was that these words were used during communication by the patients, the family, and even the physicians. This seems understandable, given that previous literature documents that clinicians have used metaphors to impart new information to patients and inculcate language in their clinical practice, which is easily understandable for patients and their families, thus allowing them to understand



the illness from their life experiences (Periyakoil 2008). From the patient's perspective, it seemed as if utilizing words alternative to cancer provided the patient's ability to deal with her illness.

# Avoiding the "C-word"

There was a deliberate attempt at different levels (physicians, patients, and family members alike) to avoid the use of the word "cancer", "Nobody uses the word [cancer] at home. The doctor herself does not use the word." This practice occurs despite the fact that the word "cancer" has been seamlessly admitted to local languages and is understood by all, and the word has entered the vocabulary of the layperson. A previous study from Iran has also documented that the use of the word "cancer" is avoided deliberately due to the negativity associated with it (Beyraghi et al. 2011). A respondent stated, "taking the name just increases the tension in the patient. The senior doctor did not take the name till the end." In this narrative, there is a deliberate attempt to not use the word "cancer," especially because it seems to magnify stress and fear in the patient. The manner of speech employed by the patient, utilizing third person as opposed to the first person also highlights the fact that there is an attempt to distance herself from the disease.

Physicians also did not name the diagnosis outright, "She [the doctor] first told me your report is not good." However, patients expected this practice, "I had an idea what my problem was. For patients like me, this [not using the word] is better." She also went onto say, "If my doctor would tell me directly that 'lady you have cancer', I would be finished then." In fact, she recounted her first interaction with an oncologist, who spelled out the diagnosis bluntly, a practice she found "harsh" and "insensitive." The conversation with the healthcare professional reinforced this, when she recounted that patients coming from other institutes often complain that "the doctor bluntly said that you have cancer. Is that the way to speak?" The consultant further went on to say that in her opinion, no one wants to hear the word "cancer", but rather, if you tell them, "Yes, there is some illness present," patients gradually come to an understanding about their disease. Comments made to patients including "The report is not good" and "we will run more tests" allow physicians to not use the "C-word," but communicate that the outcome may be bleak.

The avoidance to name the disease occurs due to different reasons:

### i. Fear of Death

For many patients, the disease "cancer" signified imminent death. As the interview with the daughter of the non-Urdu-speaking patient showed, this reluctance stemmed from the fact that family members want to "protect" patients. While the treating physician had told the daughter that her mother had cancer, and would require a mastectomy, the daughter had concealed the information from her mother (who could not understand any language other than her native tongue). She had simply told her mother that a "small operation" was required. After the surgery, the mother asked the reason for breast removal, upon which the daughter replied, "This was done to prevent the rasoli [mass] from spreading." When asked as to why she hid the diagnosis from her mother, she replied, "This disease is life threatening. But the disease does not kill a



person as quickly as telling her that your death is on its way." While she acknowledged that the mother's time to live was limited, she believed that knowing her diagnosis would lead her mother to "live in fear" and that "the thought of death is karwa [bitter] but so is fear of the grave."

The fear of death therefore may lead to this behavior. Christoph Wilhelm Hufeland, a physician from the nineteenth century is reported to have said, "To prophecy death is to cause it" (Lee and Wu 2002). This perhaps is true at the present, because in this study, for many patients and their family members, the word cancer was equated to a prophecy of despair and imminent death. This is comparable to literature from elsewhere, which reports a similar reluctance to use the word "cancer" when communicating with patients (Al-Azri et al. 2014, Chittem and Butow 2015). In another study from Iran, a doctor said, "I can't remember the last time I used this word (cancer)... We speak about everything during the visits, except this word." Terms used in Iran are translated as "extra meat" and "illness" (Zamanzadeh et al. 2013).

# ii. Retaining Hope

Another fundamental concept of healthcare is the providers' role in ensuring that their patients retain hope. In this line of thought, it becomes understandable that healthcare professionals avoid using the word "cancer" or detailing this diagnosis to the patient, in order to ensure that patients keep their hope alive. As one of the participants stated, if she was told directly that she had cancer, she would "just be finished." The use of the word "finished" here symbolizes losing all hope, in the face of cancer. With limited disclosure of the life-threatening disease to her mother, the daughter also ensured that her mother's hope would be kept alive. As Stempsey (2015) states:

Virtually all activities of health care are motivated at some level by hope. Patients hope for a cure; for relief from pain; for a return home. Physicians hope to prevent illness in their patients; to make the correct diagnosis when illness presents itself; that their prescribed treatments will be effective.

In current times, this feeling of hope may be regarded nothing as more than a philosophical, esoteric notion; however, there is scientific evidence available indicating that feelings such as faith, hope, and charity are important virtues in people interacting with cancer patients. Hope has been identified as one of the most essential components; it has been known to add to spiritual healing of trauma and positive outcomes in distressing situation (Felder 2004). Literature also states that to maintain one's own level of hope, patients often take information selectively, and patients tend to completely rely on their doctors (Leydon et al. 2000). Therefore, this emphasizes upon the responsibility placed upon physicians to ensure that they employ words, and reveal information in a manner that is not distressing to the patient.

### Nuances of Language in the Disclosure of the Disease

The healthcare professional, a senior consultant running a busy practice in Karachi for more than 20 years stated, "Once the women gets cancer, her whole family gets



cancer." The purpose of this interview in itself was to understand the different ways that a disease, such as breast cancer is disclosed to patients and family members. In her opinion, the task of the healthcare professional is not to only provide medical treatment, but also take into account the physical, emotional, psychological, and financial issues attached. After all, "it's a tremendous stress on the whole family."

While there is an avoidance to use the word cancer, as detailed above, healthcare professionals often begin by saying things like, "I have Shak [suspicion] but let's wait for the report." In fact, if the word cancer itself is used, the immediate reaction of the patient (and family members) is numbness. However, this practice did not translate into lack of awareness on part of the patient about their diagnosis. This was illustrated in comments, such as "Nobody took the word, but I just knew" and "Even though nobody mentioned the word cancer, I realized because there were so many tests being performed." Also, the dynamics of participants of this study were also such that patients had a clear understanding about presence of the disease (except for the female participant who only spoke her native tongue). After all, they were being treated for it. In addition, patients also pick up cues when they are waiting to see the physician—they talk to other patients in the sitting area as they wait for their turn to see the physician.

This, however, may not be typical of Pakistan only. A study from Greece shows that despite changing trends with respect to disclosure of disease, the use of the word cancer is still avoided, due to clinicians' belief that this makes it easier for patients to cope with their illness (Tsoussis et al. 2013). The study also highlights that through this practice, patients cope with an illness that has essentially gives a verdict of how finite life is. To us, it also appears that harsh facts about life are perhaps better accepted in a piecemeal manner over time.

This manner of disclosure was not limited only to physicians, but also family members, who as mentioned above, concealed the diagnosis from the patient. Family members also exhibited protectiveness, for example when "nobody says a word at home." This is common in Pakistani culture, which is largely collectivistic. Disease disclosure when compared in the USA and Japan in one study concluded that in the former country, disclosure was a more standardized practice. In the Japanese study, it was found that the amount and the dynamics of the disclosure were mediated by the family and physician (Ruhnke et al. 2000). This holds true for most clinical practices and family dynamics in Pakistan, as evidenced through this research.

However, this trend cannot be generalized to all of Pakistan. A 70-year old female patient, mother of ten children and grandmother of many, representing the "head of the family", stated "It is better to tell [the patient] everything. By hiding information, it increases anxiety. I think every woman can bear it." This reinforces the responsibility on physicians and the role that they have to play in ensuring that they understand the patient, and respond appropriately. In the interview with the daughter of the patient who spoke her native tongue only, it was inquired whether she would find it acceptable if she was placed in her mother's situation (with information about her illness kept from her). She replied, "I am a person of this world. I would want to know. But my mother ... she is a simple lady. She does little in her life except pray." This perhaps emphasizes the importance of physicians tailoring their communication styles according to the needs of the patients. In addition, the healthcare professional also stated that she has witnessed a change with educated and working women—such patients want to be primary decision-makers and want full disclosure of the disease, instead of family



members mediating the treatment process; however, the nuances of language was important for them too.

Previous literature has explored perceptions of patients' desires to know about their illness. A study from England showed that a useful way to find out how much the patient would want to know is to first listen to the patient narrating his/her story and then proceed. This allows the clinicians to understand the requirements of the patients; by first making sense of the language they employ (Lanceley and Clark 2013). A study from Iran on terminally ill patients showed that patients may not want to hear the diagnosis of cancer, since that may induce depression in itself. What patients; however, require is that physicians reflect on the way information ought to be given to the patient. This is a daunting task but as one respondent from the study states, what patients really want is hope, and he adds "the truth and nothing but the whole truth should only be kept for the courtroom and not hospitals" (Glick 2011).

Keeping away information from patients may be misconstrued as deception as part of medical professionals and not justified ethically (Edwin 2008). However, certain situations may warrant that information is disclosed in different encounters, as opposed to only one (Sokol 2007). For example, refraining from using the word "cancer" may work for the benefit of patients, as our study points towards. This is not limited to Pakistan. While 88% of Greek medical professionals in a study believed that patients have the right to know about the diagnosis of cancer, 90% of those enrolled in the study stated that they avoided using the word "cancer" during disclosure (Tsoussis et al. 2013).

## **Conclusions**

Our study therefore recognizes that the language employed during physician-patient communication is important. Clinicians in their readiness to impart the truth may come across as less than empathetic, which may cause harm to the already suffering individual. Also, understandably due to low literacy rate in the country, there are no standardized practices of breaking bad news in Pakistan, which makes disclosure a difficult task for clinicians. Experiential learning, with respect to how physicians disclose the disease to different types of patients is important.

At the same time, it would also not be wrong to assume that disclosure is possible while refraining from using the word "cancer". We highlight that despite the physicians not explicitly naming the disease, almost all patients were aware of their condition, and in reality, most of them preferred physicians to break the news gently. The onus then comes on the physicians to ascertain preferences of patients with respect to how they want the news to be broken to them, and the amount of information to be imparted. Breaking bad news within clinical encounters may also mean that certain words may be used, the more threatening words such as cancer be avoided, allowing the patient to accept the diagnosis gradually, and to also retain hope.

The implications of our study are far-reaching for doctor-patient communication, and holds lessons for clinicians, who are dealing with serious and life-threatening conditions. We believe that such studies ought to be undertaken in the future, with larger sample sizes, in other locations, and dealing with different types of cancer and other debilitating illnesses, thereby informing clinical practice.



**Acknowledgements** Bushra Shirazi would like to thank and acknowledge some individuals without whom this study would have been impossible. Dr Rufina Soomro whose patients she interviewed and Prof Farhat Moazam, her mentor, who took her through this experience of qualitative research and changed her perspective towards research as a whole. Finally, both authors would like to thank and acknowledge Prof Aamir Jafarey who provided help and guidance in writing this manuscript.

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