Sexual Concerns among Indian Gynecological Cancer Patients: A Qualitative Analysis

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ABSTRACT
The objective of the study was to analyze the sexual concerns of cancer patients suffering from gynecological cancers and reasons for non-communication between doctors and the patients on these issues. The study was conducted among 38 women in whom the diagnosis of gynecological cancer had been made approximately three months earlier in a Secondary Care Centre in Indian State of Punjab. An interview guide was used to collect data and data were analyzed thematically using 'framework' method of qualitative data analysis. Findings revealed body image concerns, fears related to sex such as painful sexual intercourse and the spread of disease or recurrence of disease as a result of sexual intercourse, and non-communication among doctors and patients on sexual issues. These are important issues that often go unnoticed and unanswered, and there is an urgent need to address sexual issues in an Indian setting. It can be concluded that there is a need to strengthen the sensitive communication between doctors and their patients on sexual issues so as to improve their quality of life.

KEYWORDS: Cancer, India, Sexuality, Body Image Concerns

INTRODUCTION
Sexuality among the patients with gynecological cancers (cancers of cervix, ovary, uterus, vagina and vulva) is a major concern among Indian women but is often ignored. When referring to sexuality, a distinction should be made between the term sexuality and sexual functioning. “Sexuality is a personal expression of one’s self and one’s relationship with others” [1]. “Sexuality encompasses feelings about one’s own body, the need for touch, interest in sexual activities, communication of one’s needs to a partner, and the ability to engage in satisfying sexual activities” [2]. In contrast, sexual functioning refers to areas of functioning such as vaginal lubrication, frequency of sexual activity and breast sensitivity [3]. The cancer patients and the survivors are at a high risk of developing altered sexuality [4]. Unlike other physiological side-effects of cancer which diminish over time, altered sexuality can persist for many years into survivorship [5]. The many physical changes which occur as a result of cancer and its treatment including weight loss, hair loss and scarring, all have the ability to negatively affect a woman’s body image. Other studies have also shown that women experience a disruption of their body image following diagnosis and treatment for gynecological cancer [6-9] and may feel sexually unattractive [10]. The present study is an attempt to qualitatively analyze the sexual concerns among Indian gynecological cancer patients.
MATERIALS AND METHODS
The study was conducted in a Government Hospital in District Faridkot which falls in the famous 'cancer belt' of Indian State of Punjab, India. The participants in the study were 38 women in whom diagnosis of gynecological cancer had been made approximately three months earlier. A total of 52 gynecological cancer patients were undergoing treatment in the hospital for more than three months. Only 38 out of a total of 52 gynecological cancer patients were chosen as others were advanced cancer patients. The quasi-participant observation and the interview guide were the tools used for data collection. Interview guide was refined after the pilot study at the same hospital. All the participants were repeatedly interviewed at their follow-ups in the Government Hospital (to observe the interactions between doctors and patients) and at their native places (to study their sexual concerns in a larger familial context). All the participants were interviewed only after obtaining an informed consent from both the patient and their caregiver. The participants were assigned anonymity in the writing of the findings. The ethical approval was also obtained from Panjab University Institutional Ethics Committee for conducting the study.

RESULTS
Each interview was tape-recorded with the patient's permission and then transcribed. The data were analyzed using 'framework' method of qualitative data analysis. The transcripts were studied for themes that repeatedly appeared in the narratives of the participants. This framework of themes and patterns generated an index of major themes which were assigned numbers. The segments of text were numbered according to numerical codes from the index. Charts were then constructed for major themes.

The mean age of all participants in the present study was 47.84. The majority of them were in the age group 41-50 years, undergoing active treatment and diagnosed with cancer for more than three months.

The sexual concerns among Indian gynecological cancer patients include body image concerns, fears related to sex such as painful sexual intercourse and the spread of disease or recurrence of disease as a result of sexual intercourse, and non-communication among doctors and patients on sexual issues.

Body Image Concerns and Fears Related to Sex
Gynecological cancer patients suffer from a number of sexual concerns which are often unnoticed and unanswered. It was found that the female patients with gynecological cancers face the problem such as body image concerns, uncertainty, fear of painful sexual intercourse and recurrence of disease.

A participant (aged 45 years) considered uterus as a symbol of womanhood and the removal of which leads to loss of identity. She related this loss to the identity of a transgender whose sexually identity is not defined and clear in the society as she narrated, “I do not want to be a transgender”. Another female (aged 43 years) narrated, “I want to die as a woman” on being suggested the surgery for removal of her uterus.

Further, it was found that the obligation to fulfil their roles as women and as wives lead these cancer patients to indulge themselves into the sexual activities inspite of constant fear, pain and suffering. The cancer patients also fear that saying “no” to their partners would mean loss their femininity and sexuality. The submissiveness of women appeared as these women assume that demand of their husbands to have sex is completely natural and legitimate, and it is their duty to oblige them. Thus, these patients faced a number of sexual concerns but due to non-communication on these issues made it even more difficult for them.

Lack of Communication between the Doctor and Patients on Sexual Issues
Gynecological cancer has been shown to affect women’s sexuality, yet the evidence suggests that sexual concerns have long been neglected in health care [11]. The barriers to providing sexuality information are lack of time, lack of knowledge, a person’s attitudes about sexuality and patient’s lack of readiness [12]. The reasons for not discussing sexual issues between doctors and gynecological cancer patients include the attitude that ‘it is not my responsibility’, embarrassment, lack of knowledge and experience, and lack of resources to provide support if needed [11]. Though the health care
professionals believe sexual concerns to be important but they rarely discuss them [13]. Similarly during medical encounters, the patients may directly verbalize that they have concerns, or even be fearful about their condition but may not be ready to ask questions. The fact that women ask fewer questions or ask none, does not necessarily mean that they have no questions. In the present study, the participants were about their sexual concerns. The majority of their concerns relate to sexual dysfunction and fear of resuming sex after the treatment but a non-communication between doctors and the patients was found due to time constraints, focus on treatment than on communication and rapport establishment, age and gender differences between patient and doctor, and cultural insensitivity.

i) Time Constraints and Focus on Treatment than on Communication and Rapport Establishment: The communication between a doctor and a patient is very important for patient’s quality of life and well-being. The major barrier in communication and seeking information regarding sexual concerns among the rural Indian gynecological cancer patients was found to be the time constraint. It was found that doctors focus more on treatment than on communication and rapport establishment with the patient. The patients feel it difficult to understand whether the discussion related to sexual issues is relevant or not and expect their doctors to answer all their queries before they actually ask. This happens due to lack of rapport establishment by the doctor to the patients.

A female respondent (aged 36 years) narrated “I expected that he (doctor) would tell me by himself” as she wanted to know about whether to resume sex or not and if yes, when to resume and whether it would affect the disease status or would it be painful.

ii) Age and Gender Differences between Patient and Doctor: The age and gender differences between patient and doctor was another important factor that affected the communication between the two. It was found that the female patients do not feel comfortable discussing their sexual concerns with their male doctors and especially those who were younger in age. Most of the aged women reported that they feel uncomfortable asking questions related to their sexual concerns from younger male doctors. As in Indian context, discussion about sexuality is uncommon and only takes place between partners and those in similar age groups and not among those with a vast age differences.

A female respondent (aged 62 years) mentioned “I feel like hell” while she undergoes medical procedure by a younger male doctor. She shared that she feels uncomfortable and equated the experience to hell. Some of the participants also believed that it is immoral to discuss the issues related to sexuality with male doctors.

iii) Cultural Insensitivity:

As medical anthropology is primary discipline addressing the interface of medicine, culture and health behavior, and incorporates cultural perceptive into clinical settings and public health programmes. The cultural perspectives of medical anthropology are essential for providing competent care, effective community, health programmes, and patient education. The concept of culture is fundamental to understanding health and medicine because personal health behaviors and professional practices of medicine are deeply influenced by culture. Thus, health care providers need to be culturally aware, sensitive, responsive, competent and proficient in order to deliver effective health care services.

A conversation between a doctor and his female patient in this context was observed. The doctor told the patient “Lady, these sacred threads would not work, take your medicine properly and regularly”. The doctor made this statement referring to the black thread worn by the patient around her neck. She did not talk or replied to what doctor said but later complained that her doctor is insensitive and does not understand what a cancer patient goes through during treatment. She told that her mother brought her the sacred thread from a traditional healer and as a respect to the feelings of her mother, she wore the thread. She argued “If not useful, it would not be harmful” The comment of a doctor can be analyzed in the context that there are cultural differences, differences in beliefs and perceptions, and in description of the disease between the doctor and the patient. The doctors think that they are actually discovering a disease rather than coming up with a culturally relevant classification. Consequently, there is little consideration of what diagnosis involves or actually means because it
would involve questioning of whole enterprise of medicine [14]. Here, health care providers need to be knowledgeable about the relationship of culture to health as culture is the foundation of everybody's health concerns and practices. Thus, in order to improve health care services, it is important to bring attention towards cultural influences on health concerns, conditions, beliefs and practices.

DISCUSSION
Anthropological contributions to medicine are based on conveying an understanding of patient's cultural backgrounds, their illness beliefs, and health-seeking behavior and motivation which can play an important role in understandings their complaints and the care they want. This enables providers to incorporate the patient into overall treatment plan that addresses not only disease but illness and sickness as well. Cultural understanding that can enhance clinical relations by addressing factors affecting access to and presentation to biomedical treatment include features such as meaning of symptoms; factors affecting the recognition of symptoms and disease; concepts of disease and illness, and theories of its causes and cures; conceptions of body and bodily functions, and their meanings; expressions of pain and sick-role behavior; emotional reactions to illness, sickness, disease and symptoms; social networks for managing sickness; contributions of culture, family and community to causation of disorders; impacts of sickness on social life, roles, behavior, work and family relations; descriptive data on how culture and social organization affect health, etc [14].

In the study, it was found that women wished to ask a number of questions from their doctors related to their sexual concerns but due to lack of communication between doctors and patients, they did not seek clarification to their queries. The factors that were found to affect the doctor-patient communication in this context are time constraints, focus on treatment than on communication and rapport establishment, age and gender differences between patient and doctor, and cultural insensitivity. The women with gynecological cancers have a number of fears relating to resuming sex after treatment in fear of spread of disease or recurrence of disease after sexual intercourse.

CONCLUSION
In order to address the sexual problems of the gynecological cancer patients, doctor's culturally-sensitive communication with the patient is very important. The doctors need to be trained to communicate more comfortably about sexual issues. In the hospital setting, a psycho-social counsellor can be of a great help. Moreover, the patients should be encouraged to discuss their sexual problems and difficulties with their doctors.

CONFLICT OF INTEREST
The author has no conflict of interest to disclose.

REFERENCES


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