

Women's Experiences of Sexual Problems after Cervical Cancer Treatment: Lessons from Indonesian Women

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Abstract

Cervical cancer remains the most common cancer among women. It is the second major cause of women's deaths in Asia as well as in Indonesia. Cervical cancer treatment also raises issues of long-term physical, psychological, sexual, and social adaptation. The purpose of the study was to describe and to interpret the experiences of Indonesian women who have experienced sexual dysfunction after cervical cancer treatment. Thirteen Indonesian women who were participated in this study described their experiences on the first to two years after cervical cancer treatment. Data were collected through in-depth interviews. Four themes were identified (1) physical and psychological sexual complaints after cancer treatment; (2) negative effects of cancer treatment towards intimate relationship with their spouse; (3) efforts to overcome sexual problems; and (4) women's needs for help to improve their sexual health. These study findings offer providing new insights into the experiences of Indonesian women with sexual health problems following cervical cancer treatment. This study can provide nurses and other health care providers with better understanding of the experiences, concern and needs of the cancer survivors.

Abstrak

Pengalaman Perempuan yang Memiliki Masalah Seksual Setelah Pengobatan Kanker Serviks: Pembelajaran dari Wanita Indonesia. Kanker serviks merupakan kanker yang umum terdapat pada perempuan. Penyakit ini adalah penyebab utama kedua kematian wanita di Asia serta di Indonesia. Pengobatan kanker serviks juga menimbulkan masalah untuk jangka panjang seperti adaptasi fisik, psikologis, seksual, dan adaptasi sosial. Tujuan penelitian ini adalah untuk menggambarkan dan menafsirkan pengalaman perempuan Indonesia yang telah mengalami disfungsi seksual setelah pengobatan kanker serviks. Tiga belas perempuan Indonesia yang telah berpartisipasi dalam penelitian ini menggambarkan pengalamannya pada dua tahun pertama setelah pengobatan kanker serviks. Data dikumpulkan melalui wawancara mendalam. Empat tema yang diidentifikasi (1) secara fisik dan psikologis terhadap keluhan seksual setelah pengobatan kanker; (2) efek negatif dari pengobatan kanker terhadap hubungan intim dengan pasangan mereka; (3) upaya untuk mengatasi masalah seksual; dan (4) kebutuhan perempuan terhadap bantuan untuk membantu meningkatkan kesehatan seksual mereka. Penelitian ini menawarkan wacana baru terkait pengalaman perempuan Indonesia yang memiliki masalah kesehatan seksual setelah pengobatan kanker serviks. Penelitian ini mampu menyediakan perawat dan berbagai perawatan kesehatan lainnya dengan pemahaman yang lebih baik dari pengalaman, keprihatinan dan kebutuhan penderita kanker.

Keywords: cervical cancer survivors, experience of sexual problems, Indonesian women

Introduction

Cervical cancer remains the most common cancer among women. The cervical cancer treatments also possess long term implications, in sexuality which can affect the quality of life of the cancer survivors. The sexual problem is a common impact of the cervical

cancer as the distinctive nature of the cervix to be the reproductive organ as well as gender identity of women. The women need to adapt to the sexual problem in order to increase their quality of life of the cancer survivors.¹⁻² Many studies have reported that cervical cancer survivors experience sexual problems that adversely affect their quality of life.³⁻⁵

The survivors may have experience physical sexual discomfort because of the cancer therapy, such as early menopause symptoms, malfunction of reproductive function/infertility, and sexual dysfunction due to damage of the ovaries and vagina, e.g vaginal atrophy, shortened vaginal cavity.⁶ These causes decreasing vaginal lubrication and diminished vaginal elasticity. The cancer therapy may also cause psychological sexual problems, including decreased in sexual satisfaction, impaired intimacy with the partner, lack of confidence, self-image disturbance and reduced sense of femininity.⁷⁻⁹ These problems are commonly experienced by women in Asian countries, including Indonesia.

The Indonesian women have their nature to obey and to serve the husband. The cancer survivors often force themselves to serve the sexual need of the husband for the sake of their marriage.¹⁰⁻¹¹ Sometimes this condition leads into conflict because of altered sexual function, caring relationship with a partner as well as stabilization of sexual interference with their partner. These problems are not easily resolved solely by the cancer survivors and their partner. They need education and written information regarding problems of sexuality after cancer therapy.^{1,12} In Indonesia, there are only a few talks about problem in sexuality following treatment for cervical cancer. In this study, the researcher explored experience of sexual problems after cervical cancer treatment in Indonesian women.

The aim of the study was to describe and to interpret Indonesian women experiences in sexual problems after treatments of cervical cancer. Afterwards, the meaning of these experiences were explored in such a way that nurses and others may develop new insights into the experiences of the cancer survivors. These descriptions show that the knowledge and sensitivity of nurses may increase their better understanding of the health needs of the cancer survivors. They will provide insights into the type of cares which are appropriate to help the cancer survivors in their adaptation to their lives after cancer treatment and deliver more appropriate nursing care.

Methods

A qualitative phenomenology approach is appropriate to explore meaning. In particular, hermeneutic phenomenology as outlined by van Manen (1997) was used to describe and interpret the experience of cervical cancer survivors among Indonesian women.¹³ Throughout the research, I attempted to uncover the meaning of these women experiences of being cervical cancer survivors on their every day lives. I intended to capture what the essence of these experiences, what background made for these experiences, and what benefits offer for the women from this study.

Selection and recruitment of participants. The participants in this study were women who had been selected from the cervical cancer survivors at the Cipto Mangunkusumo Hospital Jakarta, Indonesia. The woman eligible for the study must meet the following criteria: (a) cancer survivor who was treated by radiotherapy 1-2 years previously (b) free of complication of disease, (c) was willing and able to talk about her sexual problem, and (d) was physically and mentally able to follow the interview process. Thirteen of the cervical cancer survivors agreed to participate in the study. Times and locations for their first interviews were scheduled. The interviews were conducted either at the patients' home or in the hospital. Fully informed verbal and written consent were obtained prior to each interview.

Data collection. The data were collected using semi-structured conversational interviews. This kinds of interview approach would best elicit the women's thoughts and feelings as well as detailed descriptions of their experiences of sexual problem. The interviews were conducted in two stages. The first interviews were designed to give the women the opportunity to describe her experiences without interruption. These interview were tape-recorded with permission and lasted for 60 to 120 minutes, with the average of 100 minutes.

The second interviews were arranged after the identification of initial themes based on the first interview, considering the feedback from the researcher's advisors. A small number of potential themes had been identified and noted. All participants agreed to have a second interview. The second interviews lasted between 45 to 60 minutes. The entire second interviews took place at the participants' homes. At this time, participants were asked to read and comment on the initial themes and to confirm the themes as their own experience. These helped to validate the interpretation of the data and, in some cases, filled in the data gaps.

The researcher enhanced the trustworthiness of the findings by establishing the research credibility, an important criterion for evaluating qualitative research. Credibility is a term that refers to the establishment of truth inherent in the data.¹⁴ In this study, credibility was started with the researcher, who is a nurse and who has been experiencing in caring of women with cervical cancer. The researcher is also one of activist in Indonesian Cancer Foundation, who has broad connection with cervical cancer survivors within a similar culture. For these reasons, the researcher was able to build trust with the participants in discussing the intimate details of their experiences. However, the researcher was aware of how her personal and professional experiences could influence the interpretations of these cervical cancer survivors' experiences. During the interview, the researcher wrote field notes about the observations and impressions to support the participants'

statements and the data interpretation. Furthermore, advanced education in nursing cancer made me more sensitive to these women's physical and psychological symptoms as context of their experiences.

Beside the research credibility, confirmation and correction of the themes were established with the participants. The participants are considered as the experts in accurately describing and interpreting their data. The participants were asked to verify the accuracy of the findings. Each participant was given the opportunity to provide any additional information as she wished.

Data analysis. The thematic analysis of each interview in this study was conducted by selecting or highlighting approach as outlined by van Manen (1997).¹² Using this approach, the researcher read the transcribed texts and asked, "What statement(s) or phrase(s) seem particularly essential or revealing the experiences being described by these participants in this study?" The researcher then circled, underlined, or highlighted these statements. The themes selected seemed to best describe the experience of sexual problems of Indonesian women. One of the challenges of course is that themes can never completely capture the deep meaning of the experiences and are "at best a simplification an inadequate summary of the notion".¹³ In all of the interviews' result, the researcher attempted to capture the essential relationships among the significant statements selected and to prepare overall themes (an exhaustive description of the phenomenon) that best describe the women's experience of sexual problem following treatment for cervical cancer. Through a process of writing re-writing and with the guidance and input of the research advisors, the researcher described the themes.

Ethical considerations. When conducting phenomenological research, as with any research, there are a number of ethical considerations to which the researcher must adhere. Prior to the commencement of this study, permission to conduct the study was requested and received from Research Ethics Committee, Faculty of Medicine, University of Indonesia, Jakarta.

The researcher and the participants' role in the study were explained using simple language so that easily understood by the participants. This explanation included the purpose of the study, the procedure for data collection and length of interviews, and the participants' rights and obligations during the research study. Participants were assured that their participations were voluntary, they could withdraw from the study at any time, and the access to health programs and services was not contingent on their participations.

Both of the interviews were scheduled at a time and location convenient for the participants. Participants

were advised of the lengthy nature of the interviews and were told that they could take a break during the interviews, stop and reschedule an interview, or refuse to respond to questions posed by the researcher that they would prefer not to answer. Any questions that the participants had were also addressed.

Results and Discussion

Demographic characteristics of the participants.

There were 13 women took part in the study. All participants were married. The participants' ages ranged from 38 to 48 years. The average age was 40 years old. There was variation in the educational background of the participants. Five of the women had graduated from elementary school, five of them were from junior high school, one was from senior high school, one was from college with a diploma, and the remaining participant had a Bachelor's degree. While 80% of participant were the housewife, 53% of their husbands worked as the labor with the uncertain income.

Thematic Analysis Results: Physical and psychological sexual functional complaints after cancer treatment.

Cancer treatment for the majority of women may cause a range of physical and psychological sexual functional complaints. All of the participants in this study expressed pains in the intercourse due to the shortened, narrowed and less lubricated vagina. Another kind of complaints of these women is their vaginas' secret which were so sticky making them uncomfortable when having sex. The following comment highlights two women's experiences of their fear of cancer recurrence because of having blood spotting after intercourse.

"...At the first time I had sexual intercourse, it was hurt... I felt that my own [vagina] was narrowed and dry ... I guess that is why I felt painful when having intercourse with my husband..... (P1)"

".....There were three times when we did intercourse, the bleeding happened. After those times, it was no more bleeding, but I was really scared. Will the cancer reoccur? Seeing blood from my genitalia is a traumatic thing for me.....(P2)"

Furthermore, many psychological complaints such as fear and anxiety also reduced intercourse frequency and decreased sexual desire. Some women also remarked that sexual encounter is a duty as a wife and is not meant to be a pleasure for the woman.

The results of the in-depth interviews found that "decreased interest in sexual intercourse". The women reported various causes of decreased sexual interest. It was partly due to many fears such as fear of pains, fear of bleedings as well as fear of cancer recurrences. Here are the examples of two women's phrases:

"..... I am still afraid to bleed despite the fact that it did not bleed again during intercourse and I also already had your explanation about that so my sex drive still has not appear (P9)".

".....My sexual desire was also decreased. I felt sorry for my husband..... he also dropped his interest (P10)".

Negative effects of cancer treatment towards intimate relationship with spouse.

Without exception, one of the greatest changes of the women who were interviewed was the impact of cancer treatment on their intimate relationships with their spouses. All of the participants agreed that their intimacy with their spouses decreased. They expressed that they did not have any sexual arousal although most of them said that their spouse understood their health conditions. Most the women in this study described their spouses as focused on their health conditions rather than their own sexual losses. Thus, they reduced their intercourses frequency.

".....I don't think he felt deprived, no... because of my illness he was very compassionate. He was hopping I would pull through. He was afraid when I was first diagnosed.....(P4)".

There was a big difference in some women whom the spouse didn't support their health conditions. They reported that their husbands were angry or stressed when they refused sexual relationship. The women made up many reasons to avoid having sex. Furthermore, as the worst case, they allowed their spouse to remarry. A woman commented on her sadness as follows:

"..... When my husband asked me to have intercourse, I made many reasons to refuse , such as I was not in the mood or our children asked me to sleep with them and any other reasons. Sometimes, my husband got angry if I kept refusing him.....(P12)".

Most of the women spoke about how cervical cancer and its treatment affected their sexual function, included their own sexual desire. One woman said that her intercourse was too painful. It had profound impact on her life. She felt this loss both emotionally and physically and wondered about the possibility of future relationship with her husband. She said:

".....I have no desire to make love with my husband, I feel I've lost something.....(P6)".

Efforts to overcome sexual functional problems.

Many efforts were taken by the women in this study to overcome their sexual functional problems. All participants hoped their spouses would understand of their sexual functions and told to their husbands to help them. For instance, the woman asked their spouses to be more patient and would go slow approach for having sex. They also allowed their spouse to masturbate. Regarding the uncomfot during intercourse, some explored different ways of sexual position. To reduce

vagina dryness, they put oil on their vaginas or their husbands' genitalia before intercourses. Some of them also consumed herbal. Some of the women expressed their experiences:

".....Because my vagina is getting dry very quick, I always ask my husband to lubricate his penis with oil or get the water on my vagina before he penetrates me, so it prevents pain. Sometimes, my husband and I try various sexual position.....a little bit relieves my pain.....(P8)".

Two of the participants asked their husbands to give stimulation in the sensitive area to induce sexual arousals. Three of the participants said they attempted to be more relaxed, to reduce the fear and to be able to improve vaginal lubrication.

"..... my husband helped me to be ready he used to give the massage on specific areas..... my reproductive organ is usually no longer dryI felt better My husband sometimes needed the cream that you gave so my reproductive organ isn't dry (P11)".

"..... I just follow advice from you anyway..... that I need to feel relaxed firstthen I started At the first time of intercourseI could not manage It hurt because it was dry so painful now it is much better (P4)".

Women's need for help to improve their sexual health functions.

All participants conveyed that they need appropriate information from health care provider in order to keep their health and their sexual functions after cancer treatment. They believe that having suitable health care can guarantee their sexual health functions and safety. Nonetheless, one woman indicated that she had not been given enough information about sexual functional problems that could be experienced because of side-effects of cancer treatment.

".....My husband said that my vagina is short, wide, and not binding anymore. I don't know how to make it contracted again like I used to have. How to keep vagina wet like before? If it is dry, it is so painful. I never get information about it.....(P6)".

Another woman also expressed her need of information from the health care provider regarding when she can regain sexual activity safely. She needs to discuss it because her husband was angry or stressed when she was denied to have sex. She expressed:

".....When is the most proper time for me to regain sexual intercourse? Is it harmful for me? I don't want to have sexual intercourse, but my husband will get angry if I refuse him and I need help from the nurse to explain and to help me.....(P13)".

Some women said they need privacy room to have sexual counseling and sexual education since the sexuality issues are still considered sensitive. One woman said:

".....According to me, sexual education has not been given in this clinic, it needs a privacy room because the sex matter is a sensitive issue.....we can not share it to everybody.....hmm.....if a nurse or a doctor can visit our home it will be good(P5)".

The interesting issues that affected many women in this study—including physical and psychological sexual complaints that alter their intimacy relationships of the couple, their efforts to overcome the problems, and their needs of health providers to help them managing the sexual functional problems after cancer post therapy. The findings were supported by Bergmark et al. (1999) that the treatment for cervical cancer frequently results in changes of vaginal anatomy and functions, and consequently, changes in sexual function.¹⁵ The long-term consequences of radiotherapy include shortening or narrowing of the vagina and reduced lubrication.^{1,16} To date, the majority of studies of women treated for cervical cancer have focused predominantly on the physical effects of treatment on sexual function.^{1,15,17}

Other emerging themes were the negative effects of cancer treatment towards intimate relationships with their spouses and the efforts to overcome sexual functional problems. These two themes were the themes which most directly captured the sexual life changes of these Indonesian women experienced when they become cervical cancer survivors. The first theme identified that the cancer survivors' sexual problems with their spouses, such as decreasing sexual relationships frequency and sexual interests. Whilst, the second theme was used to explain or even justify acceptance of the changes they had undergone. In addition, the efforts to cope with the sexual problems were supported by the spouses. These findings are aligned with the study results of others.¹⁸⁻¹⁹

The changes that these women experienced encompass psychological and physical dimensions of sexual changes. These changes are similar to the research results in other cultures, particularly in western cultures in which most of the studies on cervical cancer survivors have been conducted. Women in this study experienced major sexual life changes after the cancer treatment. One of the sexual life changes was the sexual physical complaints that the intimacy relationship decreased. This finding supports and confirms the work of others.²⁰⁻²²

The majority of women in this study experienced physical problems, such as the vaginal change in terms of size and anatomy, which also affected their sexuality functions. The current study reveals a range of sexual problems after cancer treatment, including loss of sexual desire, dyspareunia, and vaginal dryness. The findings indicate a link between cancer treatment and sexuality mostly due to the physical problems and psychological

difficulties in maintaining an effective sexual relationship. Sexuality-related side-effects of cancer treatment may be seen as a combination of physical and psychological aspect, in which there is a connection between women's lack of interest in sexual intimacy and reduced sexual desire. On the other side, the findings examined the sexual changes and challenges experienced overcoming sexual problems. The need for the provision of sexual information following cervical cancer treatment was also emphasized.

The necessity to help the cervical cancer survivors has been identified in the literatures, especially regarding informational support. The women in this study reported a lack of information provided by the health care workers about the disease, its potential complications, and how to overcome the sexual functional problems after cancer treatment. Thus, they were unprepared for the possibility of long-term complications that might change their daily lives. Participants stated that they expected to hear this from their healthcare providers, or find someone to help them.²³⁻²⁴ Furthermore, a systematic review of information needs by patients with cancer identified information about treatment and side effects as the most commonly cited information.²⁵

The cervical cancer survivors also commented that they need an appropriate setting to discuss intimate sexual concerns. They need counseling to solve the physical complaints following cancer treatments. Similar findings were presented by Bukovic et al., (2003) who noted around 71% of cervical cancer survivors communicated the need for sexual counseling.²⁶ The challenge of meeting informational needs related to cancer treatment effects on sexuality is more complex than simply addressing the timing and environmental issues.²⁷⁻²⁸ The findings raise the question of whose responsibility is to provide information, as many women raised issues concerning the appropriateness of the context in which information related to sexual matters was provided.

Recommendations for future research and practice.

In the clinical context, the findings of the current study enable nurses in Indonesia to increase their knowledge and sensitivity so that they have better understanding on how the women adapt the changes of their sexual lives and intimacy with their partners following cancer treatments. It provides insights into the types of care that might appropriate to help the cancer survivors in their sexual adaptation. The provided data may yield a deeper understanding of the experiences of these women at an important sexual adaptation in their lives.

The education and counselling targeted to the cancer survivors and the spouse by the health professionals could also improve their sexual well-being. It should have more emphasis on the patients' initial assessment

and follow-up visits. The study findings make a valid contribution to nursing knowledge in this sensitive and important field of cancer nursing.

The current findings raise specific suggestions for further research related to cervical cancer survivors' experiences. It is acknowledged, however, that further research at multiple centres may yield different results and implications for nursing practices. It would be of value in future to conduct a multicentre prospective study, which involves a baseline and additional interviews to enable comparisons to be made.

Limitations of the study. There are some limitations identify in the present study. The first is the sexual issues are generally sensitive and tend to be ignored, especially in eastern culture. The participants of this study may have unfamiliarity and fail to be explicit when discussing their experiences and preferences. The second is, as a common matter in the qualitative study, as researcher can not assume that the sample is representative because the study was confined to women attending one cancer hospital as the research setting. Therefore, it would rather difficult to establish the transferability of the study results.

Conclusions

This small but important in-depth study has given meaning to the life experiences of the cancer survivors. It elucidated the side effects of cervical cancer treatment on altering the sexuality and intimacy of the cancer survivors and their spouses that drive their own efforts to cope with their sexual problems. Furthermore, the study has also revealed that the cervical cancer survivors may have diverse, and often poorly met, sexual information needs, which had evolved over time following their treatment. Therefore, the study findings indicate a need for treatment centres to better address the effects of cervical cancer treatment, including improved individualized information to patients and their partners.

The study adds new insights into the sensitive subject of sexual adjustment of the Indonesian women following treatment for cervical cancer. It provides nurses and other health care providers with better awareness and understanding of these experiences and with sexual information about concerns and needs of these women.

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