






HUSBANDS' PERCEPTIONS AND EXPERIENCES IN CARING FOR WIFE WITH CERVICAL CANCER: A QUALITATIVE PHENOMENOLOGICAL STUDY

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Abstract

Background: Cervical cancer ranks fourth for cancer that is often experienced by women worldwide and all ages with an estimated 604,127 new cases (6.5%), 342,000 deaths and about 90% of these cases occurred in low- and middle-income countries in 2020. In terms of psychoneuroimmunology, physical and emotional stress can have an impact on the immune system. Husband support with anxiety levels in cervical cancer patients undergoing chemotherapy, data was obtained that 7 out of 12 cervical cancer patients experience lower levels of anxiety when getting support from their husbands because patients feel more comfortable, calm and happy. This study aims to explore the perceptions and experiences of husbands while caring for their wives suffering from cervical cancer. **Method:** This research was conducted using qualitative methods with a phenomenological approach. The research subjects or informants in this study are husbands who treat wives with cervical cancer at Dr. Soetomo Surabaya Hospital who meet the inclusion and exclusion criteria. From the results of semi-structured interviews, the researcher took the following steps, organizing and preparing the data to be analyzed, reading and viewing all the data, coding all the data, using the coding as material for creating descriptions, connecting between themes, and providing interpretation and meaning about the theme. **Result:** In this study, researchers found four dominant perceptions of husbands caring for their wives who had cervical cancer. These perceptions are most participants did not know about cervical cancer, all participants felt negative emotions when they learned about the complaints experienced by wives, various forms of support were given by participants to wives, all participants hoped for the recovery of wives. In the section on husbands' experiences in caring for wives with cervical cancer, researchers found five experiences experienced by husbands. These experiences include: all participants' wives experienced bleeding complaints, all participants experienced changes in terms of conjugal sexual relations, most participants had bad concerns about wife disease, the majority of participants never used poly palliative or pain-free services, most participants hoped that administrative services at Dr. Soetomo Surabaya Hospital would be faster. **Conclusion:** Cervical cancer affects and changes all aspects of women's lives and their families including for husbands of patients, therefore the care given to cervical cancer patients should be carried out holistically

Keyword : *Perception, Experience, Husband, Cervical Cancer*

INTRODUCTION

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Cervical cancer ranks fourth for cancer that is often experienced by women worldwide and all ages with an estimated 604,127 new cases (6.5%), 342,000 deaths and about 90% of these cases occurred in low- and middle-income countries in 2020 (WHO, 2022). Data from the Global Burden of Cancer Study (Globocan) states that in 2020, the incidence of cervical cancer in the world is 24.4 million per 100,000 population with a mortality rate of 14.4 million per 100,000 population (WHO, 2020b).

According to Riskesdas 2013 data, the number of cervical cancer patients in Indonesia is quite high, 98,692 people (Kemenkes RI, 2017). In Indonesia, there were 36.633 million (9.2%) new cases, with a death rate of 21.003 million (9.0%). The figures show that there are 50 cases detected every day with more than two deaths every hour (WHO, 2020c). Cancer prevalence increased from 1.4% to 1.8% (Kemenkes RI, 2021). Cervical cancer ranks second in Indonesia after breast cancer with an incidence rate of 9.3% and a mortality rate of 8.8% (WHO, 2020a).

Based on data released by the East Java Provincial Health Office, in 2019, the number of cervical cancer patients reached 13,078 cases as the first rank and followed by breast cancer with 12,186 cases (Kominfo Jatim, 2020). Meanwhile, based on preliminary studies conducted by looking at medical record data at Dr. Soetomo Surabaya Hospital in the last five years, the number of cervical cancer cases ranked first compared to other gynecological oncology cases at the Obstetric Gynecology Inpatient Installation (Irna Obgin). In 2018 there were 1,892 cases, an increase in 2019 to 2,483 cases. In 2020 where the COVID-19 pandemic occurred, cervical cancer cases decreased quite drastically to 1,493 cases, then further dropped to 1,062 cases in 2021. The decrease in cases was due to a decrease in the number of patient visits to Dr. Soetomo Surabaya Hospital. However, there was another increase in 2022 to 1.251 cases.

Most cervical cancer patients come at an advanced stage, III B stadium and are dominated by the age of 20-59 years where at that age is still in the period of active sexual intercourse. The delay in cervical cancer patients coming for treatment is often caused by the patient's ignorance about the abnormalities of the reproductive organs experienced. This will have an impact on treatment that can no longer provide maximum results resulting in a higher risk of death (WHO, 2017).



In terms of psychoneuroimmunology, physical and emotional stress can have an impact on the immune system. Therefore, in the process of cervical cancer treatment, patients should not experience physical or emotional stress by means of good coping mechanisms. In addition to the coping mechanism that makes cervical cancer patients survive, family support. The existence of family support will have an impact on increasing self-confidence in patients in facing the treatment process of their disease (Sobar and Suhartini, 2022). There are three biggest fears when someone is diagnosed with cervical cancer are 1) worrying about what will happen to their family, 2) fear of getting sick 3) fear of disease progression (Hanprasertpong *et al.*, 2017). Therefore, social support in the form of emotional support and practical support can be used as a capital for resistance to anxiety against illness (Bernad *et al.*, 2010). Furthermore, a patriarchal culture dominates Indonesian society, causing women to rely on their husbands for health and welfare. promoting women's autonomy and spouses' involvement in women's health services are viable ways for promoting health-care consumption (Thapa and Niehof. 2013). Decisions about reproductive health in the family are influenced by socio-cultural, economic, and power dynamics inside the family (Kuponiyi and Alade, 2007).

Based on research by Suyanti *et al.* (2018) on husband support with anxiety levels in cervical cancer patients undergoing chemotherapy, data was obtained that 7 out of 12 cervical cancer patients experience lower levels of anxiety when getting support from their husbands because patients feel more comfortable, calm and happy. To optimize services, it is necessary to involve the husband of the sufferer because the husband is the closest person and gets influence in his life due to the illness suffered by his wife. This study aims to explore the perceptions and experiences of husbands while caring for their wives suffering from cervical cancer. Knowledge of husbands' perceptions and experiences in caring for wives can help relevant stakeholders to increase the husband's participation as a support system for his wife suffering from cervical cancer.

METHOD

This research was conducted using qualitative methods with a phenomenological approach. The phenomenological approach is an approach in research that explores a social phenomenon about human perception and experience, in this case regarding the experience of husbands caring for women with cervical cancer (Indryani *et al.*, 2022). The research subjects or informants in this study are husbands who treat wives with cervical cancer at Dr. Soetomo Surabaya Hospital who meet the inclusion and exclusion criteria, as for the inclusion as follows: The husband of a cervical cancer patient who is undergoing treatment at Dr. Soetomo Hospital Surabaya, Willing to be a research participant, The husband accompanies the wife fully during the hospital treatment. And for the Exclusion Criteria is Husband of cervical cancer patient who does not speak Indonesian, Javanese and Madurese actively

The sampling technique used in this study was purposive sampling. Based on the criteria of inclusion and exclusion that have been determined, 7 respondents were selected who became participants/subjects in the study. Data collection in this study was conducted by semi structured interviews about husbands' perceptions and life experiences in caring for wives suffering from cervical cancer with recording instruments, notebooks, and interview guides. After the interview, the data obtained were then analyzed including organizing the data obtained, coding data, categorizing data, compiling thick descriptions, connecting between themes, and interpreting data.

RESULT AND DISCUSSION

1) Characteristics of Research Participants

The age of participants ranged from 28 to 55 years. The education level of most high schools is 4 people, then junior high school 2 people and elementary school 1 person. The participants' jobs are all private, manual labor, workshops, meatball sellers, breeders, rice sellers, selling car spare parts and building porters. All participants were Javanese with Indonesian and Javanese skills that could be understood by researchers. Almost all participants with first marital status, only one participant with second marriage status with wife. Of the 7 participants, 3 people were couples with stage IIB cervical cancer, 3 couples



with stage IIIB cervical cancer and 1 person were couples with stage IVB cervical cancer.

The length of time diagnosed with cervical cancer in the participant partner varies from a matter of days and some even have been diagnosed with cervical cancer for a year. The visit of participants and wives to Dr. Soetomo Surabaya Hospital was the second time and some even more than ten times. In the current treatment, the length of days of treatment for the participants' wives at Dr. Soetomo Surabaya Hospital during data collection varies from the first day of care to the fifteenth day of care. The length of time the wife was treated also indicates the length of time participants in accompanying the wife. Almost all participants used health insurance, BPJS, but there was one participant who still used health insurance from the local district government, JPK (Jember Pasti Keren).

2) Husband's perception of wives with cervical cancer

After interviews with research participants, it can be concluded that some of the dominant perceptions of a husband caring for a wife who has cervical cancer. These perceptions are as follows.

a) Participants did not know about cervical cancer

Participants' knowledge was limited about cervical cancer. Participants did not know about the definition, causes, location, treatment and prevention of cervical cancer. As for some participants who could answer questions about cervical cancer, but were not sure of the answers. Knowledge about cervical cancer includes causes of cervical cancer, symptoms and diagnosis, methods of diagnosis, prevention and treatment, public awareness and education.

Ignorance of the importance of early detection of cervical cancer can lead to an increase in the number of women of childbearing age suffering from the disease. This is also influenced by the lack of activity in accessing information available through print and electronic media in the form of articles, news, discussions, expressing opinions, and so on (Sholikah, 2023). Knowledge is an important domain for the development of open behavior, and behavior-based behavior is often long-term (Sunaryo, 2017).

The husband's knowledge about cervical cancer has an impact on behavior in conducting cervical cancer screening examinations such as IVA examinations or pap smear tests. The study found that none of the participants' wives underwent cervical cancer screening. This is in accordance with the findings of research conducted by Rumaisha *et al.* (2023) which found that there is an influence of knowledge and support of husbands on IVA examination behavior.

- b) Participants felt negative emotions when they learned of the complaints experienced by their wives

Participants felt devastated, pity, shocked, sad, confused, worried, silent when they learned of the complaints experienced by their wives. According to the study of de Groot *et al.* (2005), women with cervical cancer and their partners express similar levels of concern regarding the disease and its treatment, assessment of sexuality, prognosis, and communication with the treatment team in terms of current concerns. Couples with advanced cancer show greater concern than couples with early-stage cancer. Although women with cervical cancer report more fatigue and disease disorders than men, both experience impairments in relationships, intimacy, and instrumental life.

In line with the negative emotions of participants, Oldertroen Solli *et al.*, (2019) found that men's experiences as caregivers and partners of women treated for cervical cancer have many aspects, including emotional and practical components. Loneliness, changes in sexual interactions, and the same feeling of vulnerability are the three main consequences that are especially important for men who have cervical cancer.

Concerns differ slightly between affected women and their male partners as time passes post-treatment. Cervical cancer patients, as well as their male partners, should receive effective psychosocial support. As major clinical discoveries advance, support and information must address the most pressing issues facing patients and their partners. This is because family strength refers to family resilience to stress and adaptive resources, as well



as how family internal strength and resilience can help them face life's challenges (Oldertrøen Solli *et al.*, 2019).

c) Various forms of support were provided by participants to wives

Participants provided support in different forms while caring for their wives as cervical cancer patients. Participants provided support by reporting to the doctor if the wife experienced pain, compromising and discussing with the wife, accompanying the wife, asking friends and looking at the internet, taking care of the wife's food, reminding worship to God.

When a person responds psychologically to his illness, he will go through five phases of self-acceptance, denial, anger, bargaining, depression, acceptance. The process of adaptation to changes that occur to maintain a healthy and balanced condition (Alligood, 2017). Positive coping management in participants was related to age, length of diagnosis, length of treatment, emotional and financial maturity.

Kim and Ahn (2022) discovered how breast cancer patients feel social support, family effort, and family functioning. Not only are families a major source of physical, mental, and social support for gynecologic cancer patients, but they can also be active participants in their treatment and recovery. From the results of research conducted by researchers, all participants gave full support to wives as cervical cancer patients, even not only from husbands, support came from closest family, friends and even health workers. Husband support is a form of care and affection. The husband has a considerable share in determining the health status of the mother. Good husband support can provide good motivation for mothers to check their reproductive health.

Meanwhile, one of the participants deliberately kept his wife's health secret, only his partner and closest family knew about cervical cancer suffered by the participant's wife. Support from family, friends or outside parties will affect a person's health behavior both in overcoming the disease and adapting to the conditions faced according to the self-acceptance phase which will further affect the duration of therapy. Because certain conditions such as cancer, can add to the burden, making patients and their partners

more vulnerable, the influence of intimate partners and close friends has great potential to affect quality of life (Morgan *et al.*, 2011).

d) Participants hoped for the recovery of their wives

Shally and Prasetyaningrum (2017) explained that cervical cancer suffered by his wife caused participants to be unable to carry out daily activities as usual, participants' daily activities became reduced in frequency. Participants were more resigned to God Almighty for their health condition due to the illness suffered by their wives. Despite their resignation, participants had great confidence and optimism that their wife's illness would be cured. Participants tried to seek treatment to cure diseases such as chemotherapy, radiation, and traditional medicine.

Healing has something to do with a person's resilience or defense, where there are two influencing factors, internal factors and external factors. Internal factors that influenced participants included self-confidence and optimism about their ability to help with healing. In addition, participants' sense of obligation to take care of their children, as well as participants' desire to see their children succeed and prosper, became the impetus for participants to strive for healing. Other external factors that influence are family support and social environment (Shally and Prasetyaningrum, 2017).

3) Husband's experience in caring for wives with cervical cancer

After interviews with research participants, it can be concluded that some of the experienced by husbands while caring for their wives who have cervical cancer.

a) Participants' wives had bleeding complaints

All of the participants' wives experienced bleeding complaints but the bleeding complaints felt were different, there was bleeding between menstrual cycles, bleeding after intercourse and bleeding spotting. In addition to bleeding complaints, most of the participants' wives experienced complaints of vaginal discharge. Vaginal discharge for a long time, a lot, some are clear and grainy. Complaints of pain were also felt by the participants' wives. Almost all of the participants' wives felt pain, only one participant's wife did not feel pain in her body. Then there were other complaints experienced by the participants' wives such as lumps in the lower



right abdomen, difficulty farting or bloating, slugging from the front (fistula), difficulty eating, difficulty defecating, complaints during urination and defecation, swollen legs, then from the results of the examination found white spots in the lungs and in the glands as well.

In general, precancerous lesions have not given symptoms. When it has become invasive cancer, the most common symptoms are bleeding (contact bleeding) and vaginal discharge. In advanced stages, symptoms can develop into low back or lower abdominal pain due to the pressure of the tumor in the pelvic area laterally until ureteral obstruction, even to oligo or anuria. Further symptoms can occur according to tumor infiltration into the affected organs such as vesicovaginal fistula, rectovaginal fistula, leg edema (Kemenkes RI, 2016b). However, many women ignore the initial complaints of cervical cancer such as bleeding after intercourse, pain when defecating, anemia and vaginal discharge that do not heal and do not feel the need to screen for cervical cancer because of their ignorance so that often the arrival of patients to health services is already in an advanced stage (WHO, 2017).

- b) Participants experienced changes in the sexual relationship of husband and wife

Changes in the aspect of conjugal sexual relations were experienced by all participants in connection with the condition of the wife's disease such as complaints of bleeding, pain during sexual intercourse, and vaginal discharge. Five categories of cancer-related couples' claims have been identified, such as concerns about: the function of the couple themselves; the well-being of the wife and the response to treatment; sexual activity of the partner; family and children's welfare; and the role of spouses in supporting their wives, Fletcher et al. (2010). Couples worry about changes in their sexual relationship with his wife. This covers many aspects of their sexual relationship, including quality, frequency, and lack of time to be intimate with their wives. Research conducted by Fletcher et al. (2010) is a study on breast cancer patients and their partners and found there was a change in the frequency of sexual activity.

Research by Setyowati *et al.* (2013) also discussed research that found seven themes of husbands' experiences with wives who have cervical cancer in meeting their sexual needs. The themes raised include: patterns of sexual relations after the wife is diagnosed with cervical cancer, reasons for not having sexual intercourse after the wife is diagnosed with cervical cancer. Overall, the phenomena found in this study provide an overview of the experiences and perceptions of husbands with cervical cancer regarding their sexual needs since their wives had cancer. Information support provided through counseling related to sexuality issues and emotional support from husbands is one form of health service that greatly affects the quality of life of husbands so as to encourage husband adaptation after wife is diagnosed with cervical cancer. Moreover, if there is a special study format on sexuality, it will help midwives in providing holistic care.

This is relevant to research conducted by researchers, changes in aspects of conjugal sexual relations experienced by all participants in connection with the condition of the wife's disease such as complaints of bleeding, pain during sexual intercourse, and vaginal discharge. Participants felt pity and worried that it would cause the severity of the wife's illness when having sexual intercourse. However, with smooth communication there are even participants who make jokes to their wives as cervical cancer patients can make wives entertained and feel that they still have value or meaning for participants. Changes experienced in terms of sexual relations do not make the couple reproach each other.

c) Participants worried about wife's illness

The participants' concerns were mostly that the wife died, something fatal happened, an emergency and did not recover. However, a small percentage of participants accepted the condition of the wife's illness as fate. In line with the results of research by Fletcher *et al.* (2010), married couples are concerned about their wife's response to medical care. They wanted more facts about the treatment and were very worried about the spread of cancer and it went undetected by the medical team, even when their wives were on active treatment. Couples' concerns about treatment and outcomes also



extend to the future of whether the cancer can be controlled if it recurs and where it will recur. Couples give psychological cues, evaluate themselves with self-deprecation, and worry about everything from the outcome of treatment to their ability to be supportive husbands.

d) Participants had never used polypalliative or pain-free services.

Participants never used the palliative or pain-free poly services available at RSUD Dr. Soetomo Surabaya. They never go to the service because there is no direction, get treatment from doctors and nurses in the room and the patient does not know there is a palliative or pain-free poly service. WHO categorizes palliative care as specialized medical care aimed at optimizing quality of life and alleviating the suffering of patients with serious illnesses according to Teoli *et al.* (2023). However, in this case there is a gap in the results of the study which states that almost all wives of patients as cervical cancer patients do not receive palliative services at Dr. Soetomo Surabaya Hospital.

Palliative care is usually carried out by a multidisciplinary team, which aims to alleviate all forms of suffering both physical, psychological and spiritual. Palliative care also pays attention to the patient's condition in the community, interpersonal relationships, financial resources and cultural dynamics. Palliative care providers use pharmacological and nonpharmacological therapies to relieve symptoms such as pain, dyspnea, nausea, anxiety, depression and fatigue based on Teoli *et al.* (2023).

Hospital programs can also vary, a patient must meet the criteria to be able to get palliative care. At Dr. Soetomo Hospital Surabaya, there are palliative service criteria, one of which is a pain scale worth 7-10 based on the Wong Baker FACES Pain Rating Scale, which is a calculation of pain scales created by Donna Wong and Connie Baker by looking at facial expressions that have been grouped into several levels of pain (Verizarie, 2020). There is a false belief circulating that palliative care is intended only for dying patients, patients who give up and the notion that palliative care hastens death by medicalizing the dying process. Research shows early use of palliative care can improve quality of life and prolong survival for patients

with advanced cancer. Teoli et al. (2023) mentioned that palliative care can align patient values and preferences for treatment and pay attention to the concerns and desires of family members which can be done in conjunction with curative care.

- e) Participants hoped that administrative services at Dr. Soetomo Surabaya Hospital would be faster

Participants hoped for improved services in the administration. Participants' expectations include faster queues, less long administration, and clearer, less long-winded. The participants' expectations for Dr. Soetomo Surabaya Hospital are closely related to the quality dimension of the hospital under KMKP (Quality and Patient Safety Committee). Participants as the patient's family not only assess the patient's recovery in the end, but participants also assess when the service process is provided. Based on Permenkes RI No. 80 (2020), it is explained that hospitals are obliged to improve the quality and maintain hospital service standards through the implementation of good hospital quality governance, for the implementation of certain functions in hospitals, committees can be formed according to the needs and developments of science and technology in order to improve the quality of service and patient safety.

The dimensions of health service quality for health service recipients are more related to the responsiveness of officers in meeting patient needs, smooth communication between officers and patients and families, the concerns and hospitality of officers in serving patients for recovery. For health service providers, the quality dimension of health services is more related to the development of the latest science and technology and professional autonomy in providing services according to patient needs (Mamik, 2017). As in this study, most participants hope that the administrative process runs faster so that it is necessary to apply the latest science and technology in order to achieve patient and family satisfaction so that administrative services that are in accordance with the expectations of patients and families will be achieved.



CONCLUSION AND SUGGESTION

In this study, researchers found four dominant perceptions of husbands caring for their wives who had cervical cancer. These perceptions are most participants did not know about cervical cancer, all participants felt negative emotions when they learned about the complaints experienced by wives, various forms of support were given by participants to wives, all participants hoped for the recovery of wives.

In the section on husbands' experiences in caring for wives with cervical cancer, researchers found five experiences experienced by husbands. These experiences include: all participants' wives experienced bleeding complaints, all participants experienced changes in terms of conjugal sexual relations, most participants had bad concerns about wife disease, the majority of participants never used poly palliative or pain-free services, most participants hoped that administrative services at Dr. Soetomo Surabaya Hospital would be faster.

Midwives are expected to improve effective communication skills to patients and families so that the information provided can be well understood so that the family, especially the husband, can be a support system for patients. Dr. Soetomo Surabaya Hospital should pay attention to the flow of patient services in order to achieve optimal service effectively and efficiency of service time. Improvement and addition of facilities and infrastructure should also be considered by Dr. Soetomo Surabaya Hospital as a form of healing environment that also helps cure cervical cancer patients.

DECLARATION

Conflict of Interest

Author declare there is no conflict of interest in this research.

Authors' Contribution

All author contribute from concept until writing draff article.

Ethical Approval

Health Research Ethics Committee at Dr. Soetomo Hospital, Surabaya with number 2243/104/3/VI/2023.

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Data Availability
The data supporting this research are available from the authors on

reasonable request.

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