

ORIGINAL PAPER

Psychological and sexual problems of cancer survivorsIda Ayu Made Ari Santi Tisnasari¹, Tuti Nuraini², Yati Afiyanti³, Rudi Rudi⁴, Riri Maria⁵¹ Faculty of Nursing, Universitas Indonesia, Depok, Indonesia;² Department of Basic Science and Fundamental Nursing, Faculty of Nursing Universitas Indonesia, Depok, Indonesia;³ Department of Maternity Nursing, Faculty of Nursing Universitas Indonesia, Depok, Indonesia⁴ Master of Nursing Program, Faculty of Nursing Universitas Indonesia, Depok, Indonesia;⁵ Department of Medical Surgical Nursing, Faculty of Nursing Universitas Indonesia, Depok, Indonesia.Presented as conference papers at the 8th V-BINC at FON Universitas Indonesia.

Summary *Objective: To explore: 1) the unmet needs of breast cancer patients; 2) the sexual needs experienced by breast cancer survivors; 3) the experiences of cancer patients at the time of relapse, including the biopsychosocial-spiritual aspects of their experiences.*

Materials and Methods: Interpretative phenomenological qualitative research by conducting direct in-depth interviews with participants who met the inclusion criteria.

Sample analyzed were breast cancer survivors who had experiences related to unmet needs (14 participants) or sexual problems (12 participants); adult cancer patients who experienced recurrences (10 participants).

Results: Themes identified for breast cancer patients with unmet needs were i) overcoming health problems in breast cancer survivors; ii) need to access the best health services; iii) women's unmet information needs concerning cancer treatment. For breast cancer survivors: i) information is needed to overcome sexual problems, ii) family support is needed to get sexual information, and iii) health care facilities need to provide sexual information. For patients experiencing recurrences: i) the reaction that occurs when receiving bad news; ii) efforts made during a relapse, iii) self-concept during a relapse.

Conclusions: Health-related problems of breast cancer survivors, such as fatigue and fear of cancer recurrence, can lead them to have trouble with social relationships, question their spirituality, and struggle with sex and sexuality. Oncology nurses and other professionals need to be aware of the unmet needs of breast cancer survivors, especially in relation to resolving the sexuality issues of cancer survivors. Understanding of the experiences of patients with relapse of different types of cancer should be improved.

KEY WORDS: Cancer patients; Cancer recurrence; Cancer therapy; Relapse; Resilience; Breast cancer; Unmet needs; Sexuality; Survivors.

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BREAST CANCER SURVIVORS' UNMET NEEDS FOLLOWING CHEMOTHERAPY *

(Ida Ayu Made Ari Santi Tisnasari, Tuti Nuraini, Yati Afiyanti)

Introduction

Breast cancer is the most common malignancy in women worldwide, accounting for almost one in four cancer

cases. The number of breast cancer sufferers increases annually (1), and there were an estimated 2.261.419 new cases worldwide in 2020 (2). In Indonesia, there is a high incidence of breast cancer in Bali Province. Based on data reported by Hospital in Denpasar about patient visits for breast cancer ts from August to November 2020, out of a total of 1380 patient visits, 285 were cancer patients. Breast cancer greatly affects a woman's life, and a recent study noted the importance of carrying out follow-up health checks, addressing post-treatment concerns, and improving the wellbeing and quality of life of cancer survivors (3). A high level of unmet needs in cancer survivors is associated with a poor quality of life. This condition can be attributed to the low attendance to care, which is rarely accepted by cancer survivors in Indonesia. To remedy the situation, healthcare professionals, especially nurses, should be trained to identify various problems and unmet needs experienced by breast cancer survivors so they can provide holistic nursing care (medical, psychological, social, spiritual, and cultural) for cancer survivors (4). Another study suggested that of all cancer care today, breast cancer patients represent the largest patient group with high supportive care needs (5). Accordingly, it is important to strive to better understanding breast cancer survivors' unmet needs, which should be explored in-depth. To do so, we must explore the experiences of breast cancer survivors, especially the Balinese breast cancer survivors.

Materials and methods

The research design used in this study was an interpretative phenomenological qualitative research design to examine the unmet needs of breast cancer survivors following cancer therapy. Participants in this study were selected using a purposive sampling method. The sample in this study were breast cancer survivors who had experiences related to unmet needs according to inclusion criteria set by the researcher. The inclusion criteria in this study were: i) female breast cancer survivors from various age groups, both young adults and elderly adults; ii) breast cancer survivors who wish to discuss unmet needs. The number of subjects included in this qualitative descriptive study was of 14 participants. Data was collected through in-depth interviews with all participants.

This research was conducted in March-June 2022. The study was conducted at the Hospital in Bali Province, Indonesia. This study used the researcher himself as the research instrument. The researcher collected the data by himself without a research assistant or co-researcher. The data analysis process in this study was carried out based on the research protocol, regarding the thematic approach to analysis, namely identifying, analyzing, and reporting patterns (themes) of the data (6).

Results

Theme 1: overcoming health problems in breast cancer survivors.

Theme 2: need to access the best health services.

Theme 3: unmet information needs about cancer treatment. (Details are available in **Supplementary Materials**)

Discussion

Several themes were obtained from the data analysis. The three main themes were: i) overcoming health problems in breast cancer survivors; ii) need to access the best health services; iii) unmet information needs about cancer treatment.

Each of those themes were below discussed in more detail in comparison of the existing literature.

Overcoming health problems in breast cancer survivors

The first theme that emerged through this work was the challenge that women must face as a result of the health problems they experience as breast cancer survivors. Such challenges can be physical, psychological, social, spiritual, and sexual.

Physical problems reported included memory loss and stiff joints, although the most common physical problem reported by participants was fatigue. Breast cancer survivors reported a lower quality of life than other women even years after completing their treatment due to experiencing disturbing and long-lasting side effects, including cancer-related fatigue, which can affect breast cancer survivors for many years after their treatment is completed (5). Another physical challenge experienced by the participants was memory loss. There are various research results on how memory decline or cognitive impairment can occur in breast cancer survivors. A study reported that memory loss in breast cancer survivors can be more severe in patients undergoing chemotherapy as a side effect of treatment (6). Another study similarly concluded that memory decline in breast cancer survivors could occur for years with significantly impact on the quality of life (7). Memory loss due to side effects of cancer treatment is known generally as “*chemo fog*” or “*chemo brain*” or in medical terms as cancer-related cognitive impairment. It can be exacerbated by hormonal treatment, commonly taken after breast cancer therapy (8). It is recommended that nurses are trained to provide interventions to overcome memory loss problems, such as teaching mindfulness-based stress-reduction exercises (9).

A further physical challenge experienced by participants was stiffness in their hands. According to research among breast cancer survivors in Africa, stiffness in the hands is widely experienced, along with pain (10). Another study described side effects caused by cancer treatment includ-

ing problems in the hands and shoulders and muscle strength in breast cancer survivors (11). These effects can reduce the quality of life of survivors by creating barriers to carrying out daily activities, such as dressing, combing their hair, working, shopping, exercising, etc.

Accordingly, nurses should provide interventions to help women reduce the stiffness in their hands, such as by teaching them arm and shoulder muscle exercises (12).

A further physical health-related challenge breast cancer survivors often face is changes in their appearance, such as weight loss. According to research, cancer therapy causes weight fluctuations, as well as changes in skin and nail color (13). Breast cancer survivors often feel embarrassed, lose their confidence, and have body image problems due to their changed appearance. To provide support, various nursing interventions may be directed toward increasing the confidence of women with breast cancer and survivors to breast cancer, such as running beauty care activities, holding discussions with cancer survivors, or offering cognitive behavioral therapy to women with body image problems (12).

Another challenge experienced by breast cancer survivors after chemotherapy was psychological, largely constituted by fear of recurrence. The fear was greatest when the participants felt unwell, when going to the hospital for restaging, or when they heard of others with a diagnosis or metastasis (14). They explained that after receiving cancer treatment, the transition to the life of a breast cancer survivor brings a series of challenges, the most important being the worry that remission will not last and they will one day need to resume treatment. This worry causes women to stress and affects their quality of life. Commonly, after chemotherapy, breast cancer survivors also experience social challenges due to their increased sensitivity, which prompts them to limit how much they socialize. The participants in this study stated that they assumed other people did not fully understand the situation they were facing, which implies that they were now quickly irritated and easily angered because of the chemotherapeutic drugs they had taken. This, of course, affected the participants' relationships with the people around them. They notably socialize less than they had in the past and had feelings of being unproductive. Such an outcome is in accordance with the results of other research that showed that the treatment of subjects with cancer also impacts on the people closest to them (14). All participants in this study also faced spiritual challenges, such as questioning their faith or wanting to end their life because they felt alone, despairing, like they had failed to achieve their life goals, or overcome family problems. Other participants stated they were disappointed with the hand they had been dealt or felt as if all they ever got out of life were problems. This was different from the research finding who suggested that individuals tend to turn to spirituality to overcome cancer (15). Greater overall spirituality was associated with fewer depressive symptoms and a better quality of life in individuals living with cancer or other illnesses. The researchers noted that for Latinx breast cancer survivors, in particular, religion and spirituality are essential for overcoming cancer. Although a cancer diagnosis increases feelings of vulnerability in Latinx breast cancer survivors, the cancer event strengthens their spirituality.

Spirituality is a helpful source of coping for Latinx cancer patients during both the treatment phase and the ensuing long-term survivor phase. The benefits of spirituality include a feeling of satisfaction, a sense of peace or harmony with life, and the comfort of feeling accompanied by a spiritual presence. The different findings in this study may have resulted due to factors that affected the participants' spirituality, for instance, economic factors or life events that caused the participants to fall into despair and feel disappointed with this turn in their lives. To prevent that from happening, nurses should lead spiritual-based interventions such as preparing a spiritual care program that is tailored to a patient's beliefs, supporting their spiritual well-being both as a patient and later as a breast cancer survivor (16).

Some of the participants in this study also faced challenges around sex and their sexuality, namely relationship problems with their husbands in married breast cancer survivors, or self-acceptance problems with potential sexual partners for unmarried breast cancer survivors (17). Cancer treatment can cause reduced vaginal lubrication, impaired sexual desire and arousal, pain during sexual activity, and the stigmatization of a woman as "*cancer contagious*". Such effects are hugely significant and detrimental to a women's sense of fulfillment since sex and sexuality are basic elements of human life, regardless of whether or not someone has a long-term sexual partner.

The need to access the best health services

The second key theme that emerged from this research was a need to access the best health services, with accurate cancer-detection tools and friendly nurses. Participants explained the importance of having a PET scanner and bone-scanning equipment available at the nearest hospital so that cancer survivors who wish to use these facilities do not need to travel outside the area to obtain accurate staging results. Such tools are valuable for preventing errors when detecting cancer metastases in breast cancer survivors according to research showing that bone-scanning tools are very useful for detecting the incidence of bone metastases at an early stage (18). An article previously highlighted the importance of the introduction of accurate cancer-detection tools in regional hospitals so that survivors do not have to travel far for examinations, especially those concerning the incidence of metastases, and we support that request (19).

In addition, we must note the importance of nurses adopting a caring attitude for patients and cancer survivors. Care for each survivor must be specific, based on their history of treatment. Survivorship services are usually offered in Indonesia to every patient who completes cancer treatment seeing as each therapy has short- and long-term impacts that affect the quality of life of cancer survivors (20). To improve the current offering, nurses must be trained to help cancer survivors overcome health-related challenges such as fatigue, cognitive disorders, depression, and issues around sex. Oncology nurses should understand the stages of breast cancer care so they can better understand survivors and adopt a caring attitude to meet the needs of breast cancer survivors.

Unmet information needs about cancer treatment

A final theme identified in this study was the participants'

unmet needs regarding cancer care information, such as information on the treatment stages, how to cope with the side effects of the therapy, the latest treatment information, and signposting to information technology resources to accompany their cancer care. In the research conducted among breast cancer survivors in South Korea, their greatest unmet need was in the domain of information, comprising a need for information about examinations and treatment, symptoms that need to be referred to the hospital, and how to see a doctor quickly and easily when needed (21). Paired with the results of this study, these findings should provide valuable resources for those developing new interventions in the nursing field. It is vital that health information technology is made soon applied to make it easier for breast cancer survivors to obtain the information they need regarding their cancer care.

Conclusions

The research results from this qualitative study exploring health problems and unmet needs in breast cancer survivors after chemotherapy lead us to highlight three key takeaways: i) breast cancer survivors must overcome various challenges associated with health problems; ii) they are highly motivated to access the best health services; iii) these survivors have unmet information needs about cancer treatment. A key consideration is how survivors' health-related challenges, such as fatigue, fear of cancer recurrence, issues with social and romantic relationships, and spiritual distress, can create barriers to these women attending appointments for restaging. To increase their life expectancy and the survival rate after cancer treatment in Indonesia, oncology nurses and other healthcare professionals must strive to understand better the challenges breast cancer survivors face, and accordingly, adapt their nursing practice to meet survivors' needs better.

SPECIAL INFORMATION TO DISCUSS SEXUALITY PROBLEMS: A BALINESE BREAST CANCER SURVIVOR'S UNMET NEED **

(*Ida Ayu Made Ari Santi, Yati Afyanti, Tuti Nuraini*)

Introduction

Breast cancer is the most common malignancy in women worldwide, accounting for almost one in four cases of cancer. The number of breast cancer sufferers is increasing every year (1). It was estimated that in 2020, there were 2.261.419 new cases of breast cancer worldwide (22).

In Indonesia, Bali is one of the provinces with the highest incidence of breast cancer. Based on data from *Sanglah Hospital Denpasar*, of a total of 1.380 patient visits to *Sanglah Hospital* between August and November 2020, 285 visits were made by cancer patients.

The experience of breast cancer greatly affects a woman's life. Recent studies confirm the importance of carrying out regular health checks, addressing post-treatment concerns, and improving the well-being and *quality of life* (QoL) of cancer survivors (3).

The development of technology and public awareness of the importance of early detection of breast cancer has led to an increase in the survival rate of breast cancer patients (23). An increased survival rate should be accompanied by

an increased QoL. However, in many breast cancer survivors, sexual problems affect their QoL. Sexual health concerns have been reported in 50% of cancer survivors, and the situation, if not addressed, is likely to worsen (24). Sexual issues can be complex. Problems that are often reported include pain during intercourse, difficulty achieving orgasm, and psychological struggles, such as impaired body image, accompanied by reduced feelings of femininity and sexual attractiveness, which cause the partner to be less interested. Feelings of femininity and attractiveness generally improved only after 10 months to three years after surgery. Sexual attractiveness and feeling comfortable during sexual intimacy are major problems in the first one to two years after breast surgery (23). In Indonesian society, which includes that of Bali, a woman's sexuality is not considered a basic need when she is first diagnosed with breast cancer. The situation can cause her husband (or life partner) to look for other ways to fulfill his sexual needs. This can lead to complex problems if not resolved, and a better solution needs to be discussed from the beginning. Balinese women want to display perfect breasts as they symbolize their beauty and sexual attractiveness. When they develop breast cancer, many problems follow, especially for their spouses. Balinese women are required to perform many tasks, including satisfying their spouses sexually. However, there are many things a woman cannot do when she has had breast cancer. Information about sexual needs is still a taboo topic, even though these needs are very present to Balinese women. In this study, the problem of sexual needs is explored, especially the information needed by cancer survivors to enable them to overcome their sexual issues.

Materials and methods

Research design

The design used in this study was interpretative phenomenological qualitative research, designed to explore the sexual needs of breast cancer survivors following their cancer therapy.

Sample and sampling

The participants in this study were selected using the purposive sampling method. The sample was composed by breast cancer survivors who had experienced sexual needs. The inclusion criteria were: i) female breast cancer survivors of various ages; ii) breast cancer survivors who finished their primary treatment. The sample for this qualitative descriptive study comprised 12 participants.

Data collection

Data were collected through in-depth interviews. This research was conducted between March and August 2022. The study was conducted at the oncology polyclinic of Sanglah Hospital Denpasar. The researcher collected the data by interviewing all the participants without any research assistant, so that, in this study, the researcher was the research instrument.

Data analysis

The data analysis process in this study was based on *Braun and Clarke's* (2006) description of the thematic analysis

approach, which involves identifying, analyzing, and reporting patterns (themes) of the data. In the first phase the researcher begins to record or transcribe data in written form. Then, the researcher read the results of the transcript repeatedly to find out and record emerging ideas for the next coding process. The second phase is to generate the initial coding. The third phase is developing a theme: in this phase, all the collected and coded research data are analyzed into a larger theme. The fourth phase is reviewing the requested theme: in this phase, several themes can be grouped together if they are too different. The fifth phase is defining and naming the theme: here, the researcher determines the essence of each generated theme and then refines the resulting theme for analysis. The sixth phase is reporting: this phase begins when the researcher has fully defined and analyzed a theme and writes a report on the research results obtained (6).

Rigor

The validity of the data in this study included the aspects of credibility, transferability, and confirmability. The researcher confirmed and clarified various items that have been expressed by participants. The researcher also observed participants during the interview process. The researcher confirmed data by reflecting on research results in comparison with related papers, consulting expert researchers, and confirming information with participants. The researcher also presented the results of the verbatim transcript in the research report so that the reader could assess the accuracy of the way the researcher transferred the research results to the readers and other researchers.

Ethical principles

This study had the potential to cause psychological discomfort or psychological fatigue in participants. Therefore, the researcher applied the principles of beneficence, respect for human dignity, and confidentiality. This meant that the identity of the participants was not included, or only the initial code on the informed consent form was included. This research design was approved by the ethics committee of Sanglah Hospital Denpasar.

Results

1. Information is needed to overcome sexual problems
2. Family support is needed to get information on sexuality
3. Healthcare facilities need to provide sexual information (Details are available in **Supplementary Materials**)

Discussion

Sexuality is a normal part of life. Therefore, as there has been a substantial increase in the number of breast cancer survivors, it is critical to address their QoL after treatment (23). The survival rate for women with breast cancer is increasing. Treatment regimens are accompanied by a range of physical, psychological, existential, and social concerns (23). Balinese breast cancer survivors have different issues from others in relation to meeting sexual needs since they have a distinctive culture. Nevertheless, the fulfillment of their sexual needs remains an important part of their lives.

Based on the results of the data analysis, three main themes emerged: i) the need for information to overcome sexual problems and meet the partner's sexual needs; ii) the need for support from the extended family to meet the need for information about sexuality; iii) the need for health care practitioners to provide information on sexuality.

Information needed to overcome sexual problems

Informant 1 explained her need for information on sexuality. The informants discussed the problems experienced in fulfilling their own and their husband's sexual needs, such as pain during intercourse. The informants were told that there is a gel that can help reduce pain during intercourse. Interventions using technology to increase relational intimacy and a sexual enhancement intervention for couples experiencing sexual difficulties following breast cancer have been shown to be acceptable, with a high level of satisfaction (25).

Informant 2 explained that she didn't care that her husband was cheating on her because she was more focused on her own health treatment. However, she was still annoyed with her husband and demanded him to end the affair and stay away from her. She was successful in her demands because her caste level in Bali was higher than her husband's. Informant 2 felt that her partner was no longer interested in her. She no longer wanted to serve her partner. This would have a complex impact on the integrity of the family. This couple needed counseling and information about their sexuality so that their QoL problems would not become even more complex. The husbands of women with breast cancer need support to improve their sexual and marital relationships. Education and counseling about sexual activity during treatment for breast cancer should be incorporated into healthcare programs (26).

Family support is needed to get information on sexuality

Balinese women lack support and advice from their families in relation to their sexual needs. Therefore, healthcare providers play an essential role. These women do not have the support they need. They believe that sexuality is a shameful issue, and they are reluctant to ask questions about it. Healthcare professionals need to talk about the possibility of sexual problems arising due to the changes in women's bodies caused by cancer and its treatments. These women need to be encouraged to talk about these problems, with due consideration for their religious and cultural positions (27).

Healthcare facilities need to provide sexual information

Informants 3 and 11 stated that they were ashamed to discuss their sexual needs. Indonesian society considers it taboo to discuss sexuality, even though it is a normal basic need that must be met. The attitudes of healthcare providers and survivors concerning what constitutes helpful and unhelpful communication behaviors when discussing sexual health concerns were misaligned in nuanced and significant ways (24). Providers should make an effort to find ways to communicate effectively with survivors. Informant 4 felt that the nurses and healthcare workers did not care about whether the sexual needs of survivors were met. Therefore, health workers

need sufficient information to help survivors. Zhang *et al.* explained that there is a significant gap between the providers' perceptions and the patients' needs regarding discussions on sexual health. More effort should be made to promote the communication needed regarding sexual health (28). A study showed that there is a need for healthcare providers to discuss sexual health after breast cancer with all their patients, as it is a concern that both single and partnered breast cancer survivors have to face after treatment (29).

Research implications and limitations

Breast cancer survivors have unmet needs for information, including information about their sexual needs. Cancer nursing services should be equipped to provide this information. The results of this study can provide an overview for nurses and other healthcare workers regarding the unmet needs of breast cancer survivors, especially the information needed about sexuality. This would enable nurses and other healthcare professionals to improve the quality of the healthcare services they provide by offering supportive care services that are in alignment with the needs of breast cancer survivors, thereby achieving a more holistic quality of service. In addition, the findings of this study raise the hope that there will be consultation on the problems experienced by cancer patients and survivors, which will trigger awareness of the importance of specialist oncology nurses being present in cancer care structures. Furthermore, it is recommended that more comprehensive nursing care should be provided by healthcare providers to assist cancer survivors in meeting their needs. This would result in an increased life expectancy or survival rate for cancer survivors in Indonesia. Recommendations for further research are that the unmet needs of cancer survivor couples be investigated so that new concepts relating to supportive care can emerge.

The researcher realized that there were limitations and shortcomings in this study, namely that the participants felt embarrassed to express complaints relating to the services they received at the hospital.

Conclusions

Sexuality is still a basic need of breast cancer survivors. Inaccurate information or poor communication can affect the fulfillment of survivors' sexual needs, which will have a negative impact on their QoL. Therefore, oncology nurses and other professionals need to understand the problems of breast cancer survivors, especially those in Bali, so that they can enable them to fulfill their sexual needs.

LIFE EXPERIENCES OF INDONESIAN CANCER PATIENTS WITH CANCER RECURRENCES: INTERPRETATIVE PHENOMENOLOGY ***

(Rudi Rudi, Yati Afiyanti, Riri Maria)

Introduction

A patient is considered to have had a cancer recurrence when the same type of cancer cells as when first diagnosed are found either in the same or a different place

after at least 1 year from receiving primary treatment (30). There is no time limit for determining whether the cancer is recurrent or developing, but most clinicians consider it as a recurrence if it reappears after one year of no signs or symptoms (30).

Each type of cancer has a recurrence rate that varies according to the stage, histology, genetic factors, patient-related factors, and treatment. It is believed that many recurrence rates do not take into account the latest cancer treatment options, especially when new cancer therapies are being used for certain types of cancer. Therefore, recurrence rate estimates can vary between individuals and include both high and low recurrence rates.

Some cancers have low recurrence rates if treatment occurs at an early stage. For example, patients with breast cancer who receive an initial treatment with receptor therapy followed by maintenance therapy have a recurrence rate of 5% to 9% (31).

For cancer patients, the *World Health Organization* has created evaluation criteria for classifying clinical recurrence and remission in solid tumors called the Response Evaluation Criteria in Solid Tumors, which consists of several definitions including complete response, partial remission, progressive disease, and stable disease (32). The definitions are used to assess the extent of the response obtained by cancer patients who have received different modalities of treatment such as chemotherapy, radiation, and surgery.

When a patient has a cancer recurrence, several problems can arise. For example, in a phenomenological study conducted by *Finlayson et al.*, on ovarian cancer patients who consider recurrence as a chronic disease, the patients were unable to make treatment decisions and had long-lasting emotional distress (33). According to *Shao et al.*, other issues, such as a poor financial situation, can make an impact on the *quality of life* (QoL) of patients with cancer recurrence (34). Good coping strategies are needed to overcome the problems arising after that a patient is informed to have had a cancer recurrence. In ovarian cancer recurrence, the coping strategies used have been based more on emotions and personal beliefs (35). There are no definitive data on cancer recurrence in Indonesia regarding new cases and cancer deaths. However, cancer recurrence is a significant health issue for cancer patients who experienced this problem after treatment. In addition, data regarding the varied experiences of cancer survivors in Indonesia who have had recurrences are also scarce. Therefore, data regarding the experiences of cancer patients who experience recurrences should be the subject of in-depth study in order to make able oncology nurses and other health care professionals to understand the problems and needs of these patients and to develop interventions to solve them.

Materials and methods

Participants

A total of 13 patients treated and followed at *Dharmais Cancer Hospital* who had experienced a recurrence were recruited and included according to the following inclusion criteria: i) male or female adult cancer patient who had experienced a recurrence after at least 2 months from

the declared relapse; ii) could communicate well. Three patients were not interviewed for the following reasons: one patient was afraid of trauma when talking about the recurrence, one patient had a worsening condition and had to be admitted to the emergency room, and one patient could not be contacted again after being confirmed. In total only 10 patients participated in the study.

Data collection

RD (first author) conducted data collection from March 2022 to May 2022. Data were collected via in-depth direct interviews with seven patients (one patient was recruited at the *Dharmais Hospital* as an outpatient, two patients were recruited through home visits, and the rest were inpatients), and three patients were interviewed by telephone. The researcher and each patient agreed on location and methods of interview. With the consent of the participants, interviews were recorded for 60 to 75 minutes. Interview guidelines are shown in Table 1.

Table 1.
Interview guidelines.

| No | Question |
|----|---|
| 1 | What did you experience when you had a recurrence? |
| 2 | What efforts have you made to overcome the recurrence of cancer? |
| 3 | What are the things that affect your resilience when experiencing a recurrence? |

Thematic analysis

The data analysis process was performed according to six steps (6).

RD and YA did the data transcription separately. Then, after obtaining the transcript, they read it repeatedly and recorded or marked keywords for the coding process. The researchers used the NVivo 12 application with serial number NVP12-LU001-ED030-25004-LOBI. This application was used to perform the initial coding of each interview transcript. The initial coding activity was carried out by RD with YA. The two authors then compiled the themes; namely, all the research data that had been coded and collected was analyzed to determine larger themes. The next stage was to review the generated themes and group them into sub-themes. This process was carried out by peer debriefing.

In the fifth stage, the themes were defined and named to determine the essence of each generated theme, and then these themes were refined. The final stage determined the final themes of the results of this study.

Results

Theme 1: the reaction when information about recurrence or when bad news were received.

Theme 2: the efforts made during a recurrence.

Theme 3: the patient's self-concept during a recurrence. (Details are available in **Supplementary Materials**)

Discussion

Reaction when information of recurrence was received or when bad news was received

A recurrence can be detected by the onset of symptoms like those of early cancer. These symptoms reappear at

least one year after an initial diagnosis of cancer (36). Some participants in this study expressed psychological reactions when experiencing a recurrence, such as shock, sadness, disappointment, and shame. The participants who expressed disappointment felt that they had taken care of themselves as best as they could, so why did other people who did not take such good care of themselves not experience a recurrence? Those participants felt that God was mistreating them. These experiences of the participants are similar to those conveyed in the research conducted by *Thornton et al.*, who mentioned that one of the themes found in their research was an emotion with a sub-theme of anger caused by feelings of envy because the patients felt that they had done everything correctly according to the doctors' instructions (37). This is also as stated by *Economou et al.*, who indicated that patients who received bad news felt anger and sadness early during a recurrence (38). Psychological responses to bad news can affect the QoL of patients. For example, the results of the research by *Kugimoto et al.*, showed that psychological responses to stress that can affect QoL occur in cancer patients from news about terminal conditions, disease names, and recurrences (39). Bad news must be delivered by professional health personnel, such as nurses, who must pay attention to the room's condition, time, and atmosphere so that the patient does not become emotionally stressed (40).

The efforts made during a recurrence

Some participants chose alternative treatments such as cupping or hypnotherapy before taking conventional medical treatments when they were declared to be recurrent. Some of them had used herbal treatment before the recurrence, such as drinking soursop leaves, which are believed to cure cancer. When interviewed, participants said they received information on the benefits of herbal medicines from the internet. The recurrences experienced by the participants made them stop taking soursop leaf herbal medicine as they then considered it useless. The impressions regarding treatments and herbal medicines that participants conveyed were in line with the results of a previous study that found that an average of 51% of cancer patients used alternative and complementary therapies to improve their health and treat the complications from cancer or treatments (41). A qualitative study conducted by *Abu Sharour*, on patients with colorectal cancer in Jordan found that participants sought complementary treatments when experiencing a recurrence (42).

It takes the participation of health workers, especially nurses, to convey that there are alternative and complementary therapies that are safe and recommended for patients with cancer. One of the participants in this study had difficulty urinating and drank a decoction of kumis kucing leaves as suggested by a friend. After drinking the decoction of kumis kucing leaves, the participant could urinate but continued to go to the hospital because the participant considered the kumis kucing treatment only temporary. Research by *Madyastuti et al.* stated that the kumis kucing plant (*Orthosiphon aristatus* Blume) that is easily found in Indonesia has flavonoid ingredients with diuretic activity (43).

The conventional medical therapies received by the 10

participants consisted of surgery, chemotherapy, and radiation, with no other therapies besides these were found. Previous studies have suggested that the available cancer treatments apart from surgery, chemotherapy, and radiation also include immunotherapy, hormone therapy, bone marrow transplantation, and targeted drug therapy that are conventionally administered metastatic breast cancer treatment (44).

As stated by *Birmingham Children's Hospital*, patients need to be prepared physically and mentally for chemotherapy, surgery, and radiation treatments (45). Chemotherapy is a serious medical procedure, and it must be ensured that the patient is otherwise in good health. Mental preparation creating self-efficacy has been shown to reduce emotional stress, such as in patients who are about to undergo surgery (46). Participants who received general oral chemotherapy experienced a weight loss because of the effects of chemotherapy can cause nausea, vomiting, and diarrhea. After chemotherapy, the participants experienced difficulties eating and persistent diarrhea until they were given drugs to stop the diarrhea (47). After mastectomy patients are at risk for lymphedema, which is soft tissue swelling due to the accumulation of protein-rich fluid in the extracellular space, with swelling usually in the arm or hand on the side of the body that was operated on (48). Swelling in the hands after surgery was also experienced by one of the participants, who received an explanation from a medical rehabilitation doctor that this condition can occur as a side effect. Some participants maintained the recommended diet by consuming foods that contain protein, such as fish, meat, tofu, and tempeh, and not eating satay. In another study, it was stated that one of the causes of the occurrence and recurrence of cancer is foods that contain carcinogens, such as salted fish (30).

In addition to maintaining the diet, the participants also revealed the efforts they made in maintaining a healthy lifestyle, such as exercise, routine checks, self-checking their breasts, and not smoking. Cancer patients are recommended to continue physical activity because routine physical activity can prevent cancer recurrence (30). This opinion is in accordance with research conducted by *Rock et al.*, which recommended that to prevent cancer, adults should perform a physical activity of a moderate-to-heavy intensity, depending on physical condition. Not smoking is also part of maintaining a healthy lifestyle because cigarettes have tobacco as primary ingredient that is an agent that causes cancer.

Getting closer to God when suffering from illness is another part of the efforts made for healing by asking for His help. In this study, the participants revealed the efforts that they made to get closer to God through better prayer and worship. For someone who has been able to maintain their life despite experiencing a cancer recurrence, the next stage is then personal growth. At the individual post-traumatic growth stage, the result is an increase in spiritual well-being.

Self-concept during a recurrence

This study explored various factors that can affect survival at the time of a recurrence. In this study, it was found that some participants expressed the reasons that they believed could enable them to survive their recurrences. Namely

they believed that they could recover, by having a strong motivation to recover and enthusiasm for undergoing treatment, obtaining support when undergoing treatment, and eating food appropriate for treating a recurrence. The participants who said that they believed that they were sure to recover demonstrated their optimism, while those participants who said they had the motivation to recover demonstrated their hope. The support for undergoing treatments can come from family or from sources other than family; in this study, it came from husbands, wives, children, parents, and neighbors. Patients who experience a relapse need to be given support and hope from everyone, especially their closest family members who act as caregivers while the patients are undergoing treatment. Thus, support from families (parents or children) is very important for cancer patients and those who experience a recurrence. For example, if the cancer patient is a father, they especially need support from their children.

Optimism, hope, and support are part of the direct path to fostering the survival of someone who has just undergone a stressful event, such as receiving news of a cancer recurrence, while how one interprets a recurrence can be an indirect pathway to building resilience. If the meaning is positive, then survival can be achieved, but if the meaning is negative, it will be a warning that makes the patient uncomfortable. Achieving resilience requires evaluation. If the evaluation results are positive, they will produce optimism, hope, and will ultimately have survival.

The results found in this study can be used as a basic data source for education, nurses, and hospitals to provide nursing care to cancer patients who experience recurrence. Hospitals need to prepare a special room for patients who will be given bad information such as news of recurrence so that patients can convey all their feelings after hearing this information. From this research data, oncology nursing specialists can also provide information about fact-based complementary therapies so that they can be used by patients who experience relapse. Cancer patients need to involve the palliative team from the start so that when cancer patients experience a relapse, their self-concept and quality of life are good. For future researchers, the results of this study can provide the latest information about cancer recurrence, so that it becomes data to quantitatively measure the problems and needs of cancer patients when they experience a recurrence.

The researcher realizes that there are limitations and deficiencies in this study, namely the setting of the place used when collecting data in the hospital, that was not a dedicated room because of limited space.

Conclusions

When patients receive information that they are experiencing a recurrence, psychological reactions, such as shock, sadness, and disappointment, occur. Many efforts have been made by patients to cope with recurrences, namely through non-medical activities, medical activities, lifestyle changes, and getting closer to God. This study also found a variety of factors that can influence patients when experiencing a recurrence, such as having the confidence to recover, strong motivation to recover, enthusiasm for undergoing treatment, support in undergoing treatment, and understanding of relapse. This study can help increase

our understanding of the experiences of patients with different types of cancer during a recurrence phase.

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