ประสบการณ์ชีวิตของหญิงเวียดนามที่เป็นมะเร็งเต้านม

Ho Thi Thuy Trang พย.ม.* วาสนา รวยสูงเนิน PhD**

บทคัดย่อ

ความรู้เกี่ยวกับประสบการณ์ขณะเจ็บป่วยของผู้ป่วยจะช่วยให้บุคลากรทางสุขภาพเข้าใจปัญหาต่าง ๆที่ผู้ป่วยต้องเผชิญขณะเจ็บป่วย แม้ว่าในขณะนี้จะมีองค์ความรู้ค่อนข้างมากเกี่ยวกับประสบการณ์ขณะเจ็บป่วยในสตรีที่เป็นมะเร็งเต้านม แต่หลักฐานดังกล่าวไม่ปรากฏในเวียดนามในขณะที่จำนวนผู้ป่วยด้วยมะเร็งเต้านมเพิ่มขึ้น การศึกษาเชิงพรรณนาโดยใช้วิธีการเชิงคุณภาพครั้งนี้ดำเนินการเพื่อตอบคำถามดังกล่าว ผู้ให้ข้อมูลเป็นสตรีชาวเวียดนามที่เป็นมะเร็งเต้านมจำนวน 10 รายที่อาศัยในเขตถัวเทียนเหว ดำเนินการสัมภาษณ์เชิงลึกโดยใช้คำถามนำในช่วงเดือนพฤษภาคมถึงกันยายน 2555 ข้อมูลที่ได้นำมาวิเคราะห์โดยใช้การวิเคราะห์เชิงเนื้อหา

ผลการศึกษา พบว่า มีแนวคิดหลัก 3 ประการที่อธิบายประสบการณ์ยากลำบากที่สตรีชาวเวียดนามต้องเผชิญขณะเจ็บป่วยด้วยมะเร็งเต้านม ประกอบด้วย การตอบสนองต่อการรับรู้ว่าเป็นมะเร็ง การตอบสนองต่อกระบวนการรักษา และการจัดการกับชีวิตของตนเอง โดยในช่วงแรกที่สตรีเหล่านี้รับรู้ว่าตนเองกำลังเผชิญกับมะเร็ง พวกเขาต้องผ่านปฏิกิริยาทั้งด้านร่างกายและอารมณ์ที่หลากหลาย ได้แก่ ความรู้สึกตระหนก/แปลกใจ ไม่เชื่อ โกรธ กลัวตาย เศร้าสลด และ ซึมเศร้า หลังจากที่ได้รับรู้ว่าตนเองเป็นมะเร็งเต้านมแล้ว ผู้ให้ข้อมูลเหล่านี้เริ่มคิดถึงทางเลือกในการรักษา ตัดสินใจ และเข้ารับการรักษา โดยไม่ว่าผู้ให้ข้อมูลจะได้รับการรักษาโดยทางใดก็ตาม พวกเขาเผชิญประสบการณ์ต่าง ๆ นานา ในระหว่างกระบวนการรักษา ได้แก่ ความรู้สึกวิตกกังวล ความรู้สึกกลัว การเปลี่ยนแปลงด้านร่างกาย ความรู้สึกผิด ความรู้สึกอ่อนแอ ความรู้สึกแปลกแยก ความกังวลใจเรื่องเพศสัมพันธ์ ความไม่มั่นใจในอนาคต และการมีความหวังต่อความสำเร็จของการรักษา

การจัดการกับชีวิตของตน เป็นกระบวนการและวิถีในการเผชิญสำหรับสตรีเหล่านี้เพื่อเปลี่ยนแปลงชีวิตตนเองให้อยู่ร่วมกับมะเร็งได้ กระบวนการเหล่านี้ประกอบด้วย การยอมรับโรค การเปรียบเทียบตนเองกับผู้อื่น การทำกิจกรรมที่ช่วยบำรุงจิตวิญญาณ การแสวงหาความช่วยเหลือ การดูแลสุขภาพของตน การพยายามไม่คิดถึงโรคที่เป็น และการตอบสนองต่อปฏิกิริยาทางสังคม โดยรวมแล้วผลจากการศึกษานี้ช่วยให้เข้าถึงปัญหาต่าง ๆที่สตรีเวียดนามที่เป็นมะเร็งเต้านมต้องประสบระหว่างรับการวินิจฉัยและรับการรักษา ปัญหาต่าง ๆดังกล่าวขึ้นอยู่กับหลายปัจจัยและสถานการณ์แวดล้อม เช่น สถานะเศรษฐกิจ อายุ การรักษาเสริม และการช่วยเหลือจากครอบครัวและสังคม ความรู้ที่ได้จากการศึกษานี้จะช่วยให้ผู้ที่ทำการดูแลผู้ป่วยมะเร็งเต้านมในเวียดนามสามารถวางแผนการดูแลที่เหมาะสมต่อไป

คำสำคัญ : ประสบการณ์ชีวิต มะเร็งเต้านม เวียดนาม วิจัยเชิงคุณภาพ

Background and Rationale

Breast cancer is the most common type of cancer among women in both developed and developing countries[1]. In Vietnam, breast cancer is the leading type of all cancers. The incidence of breast cancer was nearly doubled between the years 1993-1998 and 2004-2006 ($17.32/10^5$, $32.80/10^5$, respectively).[2]

Cancer is a devastated experience that threatens not only the end of one's life, but also affects all aspects of human being.[3] Research studies around the

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**นักศึกษาหลักสูตรพยาบาลศาสตรมหาบัณฑิต (นานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยขอนแก่น*

***ผู้ช่วยศาสตราจารย์ คณะพยาบาลศาสตร์ มหาวิทยาลัยขอนแก่น*

world demonstrated the impacts of the diagnosis and treatments on victims' life such as pain, lymphedema, changes in daily life, disturbed body image, weight gain, etc.[4-5] In addition to direct impact of disease on patient's well-being, perception about the disease also influences self-concept of a person. Although healthcare practitioners may understand breast cancer as assessable and curable biological and pathological changes, survivors may perceive their illness differently. It has been found that impacts of cancer on ones' life persist to the end and may continue to their offspring.[3] Several studies reported the experiences and perceptions of breast cancer survivors, which affecting many dimensions of human being.[6-8] Additionally, it is noticed from previous studies that cultural differences played an important role on perception of breast cancer and therefore; experiences and responses to illness. Doumit and colleagues revealed that patients living in developed and developing countries had different and unique lived experience of their illness.[6]

In Vietnam, a diagnosis of breast cancer is generally perceived as lifelong threatening illness. It is unusually seen that families and health professions avoid using the word cancer in order to hide the truth of having cancer from the patients. It is believed that prognosis of disease will be worse if the patient is informed the diagnosis. Data from pilot interview of 5 Vietnamese women with breast cancer revealed that several of them did not follow treatment plan or discontinued treatment regimen. There were several reasons underlying those behaviors such as fear of side-effects, being afraid of dying sooner from treatment, and do not want to be a burden for family. Participants in the pilot study also described some feelings and coping strategies to deal with their difficulties of living with breast cancer. Health providers' understanding of the difficult experiences of illness among these patients will enhance culturally sensitive care that meets patients' needs.[9]

Although many studies around the world addressed experiences of breast cancer from different cultural perspectives, in Vietnam there is limited knowledge of breast cancer experience. The aim of this study was to describe experiences of Vietnamese women living with breast cancer.

Methodology

Descriptive qualitative design was used to describe lived experience of Vietnamese women with breast cancer.

Sampling: Ten Vietnamese women who were diagnosed with breast cancer and attended the outpatient department at Hue University Hospital, Thua Thien Hue, Vietnam were recruited using purposive sampling technique. Participants were selected from patients with breast cancer who met the study selection criteria, including having a diagnosis of breast cancer at any stages, age at least 18 years and older, and ability to speak Vietnamese. Potential participants were excluded if they had a history of mental illness or cognitive impairment and/ or if they had other types of cancer.

Design: This qualitative study used guided-questions and an in-depth interview to explore experience of Vietnamese women with breast cancer. Guided questions included general open-ended questions regarding experience related to events after acknowledging diagnosis of breast cancer. Probing questions were asked during the interview to obtain richness and depth of information. During the interview, participant observation and field note were conducted to confirm the interview data, and to enhance further understanding of the participant's context. The participants were asked to complete demographic questionnaire before the interview. Each participant was interviewed at their convenient time in the private room in the hospital. The interview took between 60 to 90 minutes long. All interviews were conducted in

Vietnamese language. Translation and back translation process were conducted by the researcher and bilingual consultant to ensure consensus on how to achieve quality of translation process. Data was collected until no new data emerged from the later interviews, which was called data saturation.

Data analysis: Content analysis technique was employed to analyze data for descriptive qualitative study. Data analysis process began with repeatedly reading the transcripts phrase by phrase and line by line. Meaningful statements and paragraphs were identified and underlined as the unit of analysis. The unit of analysis was condensed or abstracted and labeled with a code. A code was assigned to each meaningful statement or paragraph. Then the various codes were organized and grouped similarly coded data into categories. Each category was linked and compared with each other to verify the emerged findings. Similar categories were constructed into themes and sub-themes. Finally, common themes were identified to illustrate commonalities in women's experiences. Regarding trustworthiness, credibility was established through data triangulation and peer review. Data triangulation obtained from participant observation, field notes, medical records and information from participant's cousins to verify and confirm accurate transcription. Peer review was conducted through discussion of the researcher's interpretation and conclusions with experienced qualitative researcher to seek mutual agreement. The rigor of the study was increased by rich description and thick description of data and audit trail.

Ethical Considerations: To protect the right of participants in this study, the research proposal and study protocol were submitted for approval from the Ethical Committee for Human Research at Khon Kaen University. To ensure privacy and confidentiality, participants were interviewed in a provided private room at Hue University Hospital.

Findings

Ten Vietnamese women, age ranged from 30 to 67, volunteered to participate in this study. All of them were married; however, three of them were widows. Educational level of participants varied from elementary school to college/university level. None of them had experienced a recurrence of cancer. At the time of interview, seven women underwent a combination of mastectomy and chemotherapy, two of them completed mastectomy and radiotherapy, and one had mastectomy as the first treatment modality with a plan for chemotherapy. Five women were Buddhists and the rest did not have any religious preferences. Six women reported that they worked full time, one of them worked part-time, two were retired, and one was unemployed.

Data from ten interviews revealed that Vietnamese women with breast cancer had 3 major experiences related to their diagnosis and treatment including response to diagnosis, response to treatment, and manage one's life. Meaning of each theme as well as codings and selected quotes are presented as follows.

Response to diagnosis: The most initial stage of experience with breast cancer for every participant was response to diagnosis. It was the first time for these women to acknowledge that they were victims of life-threatening disease, breast cancer. During this process they experienced emotional rather than physical reactions. Participants described their reactions during this stage associated with their perceptions of breast cancer. Knowing that they had breast cancer brought a lot of complex emotional and behavioral responses including shock/surprise, disbelief, angry, fear of death, sad, and depressed. The participant believed that breast cancer was considered as outcome of primarily up to supernatural power. Their explanations were reflected in their belief about role of fate, unfortunate, and God's demand in potent cause of breast cancer. As one woman stated:

"... if I were diagnosed early, I could live longer. I also went to see doctor early but he did not discover. He said that it was benign tumor, so I did not go to check again. Probably, I was unlucky ....uhm... This is my destiny" or "I think that because of the way I lived in the past, so now I had this disease..."

All reactions in this theme were illustrated in relation with their perception of cancer as life-threatening, uncurable, and unexpected disease. Age, responsibility, and family role seemed to play an important role on this experiential process. For example one young woman said:

"...at the beginning I was almost insane. I'm still young, I just had babies. My kids are so young. What could they do without me?"

Another young woman said:

"My family is in a hard time. My biggest son is studying in university. We have to make money to send him to school. Now I have this disease. What should I do?..."

In summary, response to diagnosis was the first reaction to the knowledge of having breast cancer that all participants experienced. This experience was commonly explained in relation to impacts of perception about breast cancer and treatment to their familial role.

Response to treatment: After acknowledging that they had breast cancer, several participants started to think about their treatment options, make decision to treat, and receive treatment. Along with the course of treatment process, they were engaging in many responses both physically and emotionally. Regardless of the types of treatment, participants experienced several reactions along the process. Reactions as responses to treatment of breast cancer included worrying, being afraid, bodily changing, feeling guilty, feeling weak, feeling isolated, having sexual concern, feeling uncertain about future, and having a hope for treatment success. These responses were described in detail as follow:

"My family is having financial problem when I have cancer... and I worry that it will be a burden for my husband, all debt. It takes 20 million (VND) since I have been treated...I am poor...we are farmers, and we just earned enough to live and now I have the disease..."

"After I had my breast cut off...uhm...I felt less confident....I was depressed because I suddenly lost one breast. Anywhere I went people look at me...I felt uncomfortable with that look. They always looked at me, I felt ashamed... At first, I felt confused. I got disease like this, my husband stayed away from me, even have beaten me. I felt self-pity, suddenly I got disease...he didn't come close to me. He argued with me, I felt so pity for myself."

"Nobody can be so sure about cancer that it won't come back. How do I know that it won't come back again? I am not sure at all."

"I try to complete the treatment and try to pay debt. I wish to live with my husband and children as long as possible. I hope that I can live long so that I see my older son gets marry and I have grandchildren."

There were various personal and social conditions that the participants were taken into account as they were experiencing treatment process including previous knowledge, family condition, perception about cancer and treatment of cancer, age, other people's reactions, and cost of treatment. The participants might express their reactions to treatment process differently such as crying, separating from other people, being patient, and praying for their luck. For example one participant said:

"I am afraid of cancer comming back because if it comes back, I will have chemo again. It is painful. I felt bad, discomfort, and vomited a lot. I am so afraid of it. I don't want to have it again."

In conclusion, response to treatment was reactions resulted from negative experiences and perceptions about treatment and adverse effects of cancer treatment. Women with breast cancer demonstrated these reactions differently either physically, emotionally, or spiritually.

Manage one's life: As soon as the participants became accepted that they had breast cancer they started to manage their life in order to live with cancer. Managing one's life described the process and coping strategies that women with breast cancer used to change their life when having breast cancer. This process happened concurrently with getting treatment. Therefore, the participants' experiences of treatment affected the way they managed their life as well as what they heard about cancer. There were several aspects along the process of managing one's life that derived from interview data. The participants used different coping strategies to deal with different challenges along the process. After getting diagnosis of breast cancer, all participants experienced emotional crisis. As a result they used various coping strategies to deal with those emotions including accepting disease, seeking support, comparing with other people, and having spiritual promoting activity. During the time of treatment, the participants also experienced several emotional, social, and physical challenges due to treatment effects and its cost. Comparing with other people, taking care of one's health, trying not to think about disease, seeking support, responding to social reaction, and having spiritual promoting activity were common coping strategies that these women used in facing their difficulties. Process and coping strategies to manage one's life were described as follows:

"...No one can escape. I am fine now... quite unlucky... it is my destiny, I had to be suffered. I have to accept it. No way to make it better...I am old...bamboos are old, shoots will grow... now if I die, I am ok."

"Cancer...it is not just me who have it. Today there are many people who have cancer. I am old but there are many young people that have it too. The young who gets it are so pity."

Many conditions such as age, personal characteristic, belief about cancer, and family and social support were common factors affected coping ability of women with breast cancer. As one participant stated:

"My sisters and my brothers also my cousins support me so much. They often ask about my health. They visit me every day when I am at the hospital. They talk to me... I am happier because of their encouragement."

In summary, manage one's life was described by participants as they were receiving treatment and having to cope with illness perception and treatment outcomes. Consequently, this specific theme was mostly illustrated through coping strategies that women with breast cancer used to change their life. Social support was mentioned most as facilitating factor to effective coping.

Discussion

The experiences perceived by ten women living with breast cancer in current study was categorized into response to disease, response to treatment, and manage one's life. The participants frequently described responses to disease after knowing diagnosis as shock/surprise, disbelief, angry, fear of death, sad, and depressed. The theme "response to diagnosis" was supported by trajectory onset phase in Corbin and Strauss's the illness trajectory framework.[10] It can also be described by primary appraisal in the Transaction Model of Stress and Coping of Lazarus and Folkman[11] that women with breast cancer felt harm and threatened by the awareness of having breast cancer. Therefore, they experienced a number of harm/loss appraisals such as bodily changing, feeling weak, and having sexual concern. Outcomes of threat appraisals such as shock/surprise, disbelief, angry, fear of death, sad and depressed, feeling guilty, feeling isolated, and feeling uncertain about future was resulted.

Moreover, response to diagnosis is parallel with some previous research findings. Studies by Ashing-Giwa et al[12] and Tam Ashing et al[13] showed that women's responses to breast cancer often included fear, worry, and denial. Furthermore, Elmir and colleagues[14] stated that Australian women with breast cancer had emotional responses after receiving the diagnosis of breast cancer as 'shock', 'disbelief', 'anger', 'fear', and 'anxiety'. Many other previous researches confirmed the experience of initial shock and surprise when women got a diagnosis of breast cancer.[15-18]

The theme of response to treatment which was found in the current study, described response related to treatment, including worrying, being afraid, bodily changing, feeling guilty, feeling weak, feeling isolated, having sexual concern, feeling uncertain about future, and having a hope for treatment success. Those experiences in "response to treatment" can be explained in terms of patients' adaptations in unstable, acute, and crisis phases of the illness trajectory framework.[10] Several previous researches supported finding on response to treatment. Gurm and colleagues[19] found that Canadian Punjabi-speaking South Asian women experienced social isolation during their treatment process. Other researches reported that women with breast cancer experienced hope,[3,20] uncertainty,[18,20] and body image/self-image change.[21] Al-Azri and colleagues[22] showed that breast cancer victims were at risk of developing several psychological morbidities such as depression, anxiety, fear of dying, sense of aloneness, and sexual and body images problems. Fear of reoccurrence, fear of pain; and uncertainty were found to permeate the life of all participants in one study.[23] Additionally, women in some studies reported that they experienced feeling of weakness after breast cancer treatment.[24-25] In conclusion, previous researches documented similar findings that women with breast cancer had experienced psychosocial and physical difficulties during their treatment process.

Findings of this study reflected the ability of Vietnamese women to live with the diagnosis of breast cancer and subsequent impacts on their lives. Depending on each stage, the women with breast cancer had different coping strategies. Trajectory phase in the illness trajectory framework[10] explained several ways to cope with illness and treatment among women with breast cancer in this study including accepting disease, comparing with other people, seeking support and having spiritual promoting activity. Moreover, the participants also had a number of methods to deal with difficulties during the time of treatment, including comparing with other people, seeking support, taking care of one's health, trying not to think about disease, responding to social reaction, and having spiritual promoting activity. These reactions can be described with comeback phase of trajectory framework. Similarly to this finding, Lazarus and Folkman[11] revealed that after primary appraisal, people would find coping strategies to deal with life situation. There are two forms of secondary appraisal in order to cope with situations including problem-focused and emotional-focused forms of coping. In current study, the participants reported several problem-focused coping strategies involved taking care of one's health. Similarly, emotional-focused coping strategies also highlighted by all participants such as accept disease, compare with other people, trying not to think about disease, seeking support, responding to social reaction, and having spiritual promoting activity.

Previous studies found similar self-managing process among women with breast cancer. Obeidat and colleagues[7] found that Arab American women accepted breast cancer diagnosis by using religious practices for coping, maintaining a positive attitude towards the diagnosis and the treatment, and seeking related information. Loveys and Klaich[18] stated that women with breast cancer experienced acceptance of the illness, social interaction or support, and making comparisons to adjust disease to deal with breast cancer. Study conducted by Tam Ashing and colleagues[13] showed that having a positive attitude, accepting the illness, not thinking too much about cancer were the coping strategies used most among Asian American women with brest cancer. The findings from other studies indicated that women seeked social support as a way of coping with their breast cancer.[15,20] Fu and colleagues[26] showed that women in their study used some strategies not only to face the reality of diagnosis but also to realize of not being alone with breast cancer and to move on taking good care of self and changing temperaments.

Conclusion

This study illustrated the experience of Vietnamese women with breast cancer, using a descriptive qualitative approach. The participants shared their stories that revealed three themes including initial response to diagnosis, response to treatment, and manage one's life. Several conditions and circumstances influenced their perceptions and responses as they experience breast cancer such as age, personal characteristic, type of adjuvant treatment, and family and social support. Findings from this study reflected a variety of problems that Vietnamese women confronted during diagnosis and treatment process. In addition, awareness and acknowledgment of these data will enhance nurses to provide appropriate and culturally sensitive nursing care to promote a better living of the cancer survivors.

Limitations of the Study

Although this study provides rich information about the experiences of Vietnamese women with breast cancer, there are some limitations. Firstly, all participants were from central Vietnam, married, had low economic status, and had no breast reconstruction. Only patients who had mastectomy and came for follow-up or adjuvant therapy could be reached in this study. Patients who were newly diagnosed would come for treatment when they were ready. Therefore, study findings are limited to generalization of the women with the similar context only. Secondly, each participant was interviewed only once without the possibility that the researcher's interpretation of interview data was confirmed by the participants. However, richness and consistency of interview data supported findings.

Implications

Findings from this study indicated holistic views of women with breast cancer that can be used as baseline data when applying nursing process to care for these patients. Nurses should provide care for women with breast cancer in Vietnam in order to support client's needs appropriately. Moreover, nursing intervention program should be developed to support various needs.

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Experiences of Vietnamese Women with Breast Cancer

Ho Thi Thuy Trang M.N.S.* Wasana Ruisungnoen PhD**

Abstract

Knowledge about patient's experience with illness condition promotes health caregiver's understanding of different problems a patient encounters. Although a great deal of research worldwide described diverse difficult experiences of women with breast cancer, such evidence is lacking in Vietnam in spite of increasing numbers of breast cancer victims. This descriptive qualitative was conducted to fulfill the gap. Study participants were ten women with breast cancer in Thua Thien Hue, Vietnam. In-depth interviews using guided-questions were conducted from May-September 2012. Content analysis was used for data analysis.

Three themes derived from interview data that described difficult experience of Vietnamese women with breast cancer including response to diagnosis, response to treatment, and manage one's life. Response to diagnosis, first immediate responses to knowing that they had breast cancer involved several emotional and behavioral reactions including shock/surprise, disbelief, angry, fear of death, sad, and depressed. After acknowledging that they had breast cancer, several participants started to think about their treatment options, make decision to treat, and receive treatment. Regardless of the types of treatment, participants experienced several reactions along the process. Responses to treatment of breast cancer included worrying, being afraid, bodily changing, feeling guilty, feeling weak, feeling isolated, having sexual concern, feeling uncertain about future, and having a hope for treatment success.

Managing one's life described the process and coping strategies that women with breast cancer used to change their life when having breast cancer. It included accepting disease, comparing with other people, having spiritual promoting activity, seeking support, taking care of one's health, trying not to think about disease, and responding to social reaction. In conclusion, findings from this study reflected a variety of problems that Vietnamese women confronted during diagnosis and treatment process. Those difficulties depended on different circumstances and conditions such as economic status, age, types of adjuvant therapy, and family and social support. Knowledge from this study enlightens caregivers to provide appropriate care for these women.

Keywords: lived experience, breast cancer, Vietnam, qualitative research

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**Student of Master of Nursing Science (International Program), Faculty of Nursing, Khon Kaen University*

*** Assistant Professor, Faculty of Nursing, Khon Kaen University*