

Data

Trends and Issues Related to Studies on Nursing Care for Young Women with Breast Cancer

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Abstract

Aim : This study aims to examine the trends and issues in Japanese and foreign research papers on nursing care for young women with breast cancer. **Methods :** We searched the online version of the CINAHL and Ichushi-Web Ver. 4 for the keywords “breast cancer”, “young women”, and “nursing” or “care.” **Results :** 14 papers were chosen for analysis. The research themes pertained to sexual and reproductive health, cancer experience, the role of the family, and rehabilitation needs. **Conclusion :** This study found that research on nursing for young women with breast cancer was still in its infancy. We expect that, in the future, foundational research on young women with breast cancer will be undertaken, not only overseas, but in Japan as well, and that there will be active efforts to create nursing support methods for these young women.

Key words : young women, breast cancer, nursing, literature review

Introduction

In Japan, over 60,000 women are diagnosed with breast cancer per year (Matsuda, 2013), and this number is predicted to rise in the future. Unlike most cancers, that have a peak morbidity in patients who are 60 years or older, the peak morbidity for breast cancer patients is during the late 40s (Matsuda, 2013). More recently, the incidence of breast cancer in women under the age of 39 is slowly increasing (Matsuda, 2013).

Breast cancer, unlike most other cancers, is accompanied by losing a part of the female identity. Because the treatment course can be prolonged, the physical pain and mental distress of breast cancer patients is very strong. Breast cancer in those under the age of 35 (early-onset breast cancer) is more often HER2 (Human Epidermal Growth Factor Receptor Type2)-positive, and not a hormone-

sensitive cancer. In addition, it is characterized by a high incidence of triple-negative breast cancer that is not express the genes for estrogen receptor, progesterone receptor, or HER2 (The Japanese Breast Cancer Society, 2012), and treatment is often prolonged.

According to Levinson, most people undertake self-development and expand their social role in their 20s and 30s (Funashima, 2011)-e. g., marriage and childbirth. Hence, when young women are diagnosed with breast cancer, they think of their future as women and become isolated because they do not want other people to know about their disease. They experience a great shock or a series of shocks from breast loss, chest scars, treatment stress, body image disorders, and lowered self-esteem (Abe, 2006). As for the psychological reactions and acceptance of breast loss, most research studies with age-group comparisons have reported

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that more young cancer participants had higher levels of anxiety regarding issues beyond the disease, such as changes in appearance and arm function. This group needed even greater levels of continuous nursing care (Matsuki, 1992; Saito, 2002).

Despite many indications that young breast cancer patients face particular problems, these issues have only recently been studied in Japan, with few research papers focusing on young breast cancer patients. Therefore, it is imperative to investigate nursing care methods for young breast cancer patients who suffer significant distress while also living with cancer.

To help provide nursing support for young women with breast cancer, we decided to review the existing literature (Japanese and English-language research) for trends and issues the related to nursing care for these women.

Methods

1. Selection Process for Research Papers

To evaluate the foreign literature, we performed a search for the keywords “breast cancer,” “young women,” and “nursing” or “care” using the Cumulative Index to Nursing & Allied Health Literature (CINAHL) Web version to extract papers on nursing for young women with breast cancer. We included only papers published in English.

To evaluate the Japanese literature, we searched the *Igaku Chuo Zasshi-Web Ver. 4* for the keywords “breast cancer,” “young women,” and “nursing” or “care” in Japanese. In both searches, we limited the search period to the years 2000 to 2014 in order to ascertain recent research trends.

We selected only academic papers to target those with original content and results that had academic value, we excluded reference materials, conference proceedings, and commentaries. We read each extracted paper’s title, keywords, and abstract. After investigating its relationship to nursing for young women with breast cancer, we read the full paper, confirmed its alignment with our aim, and then, if appropriate,

selected it as a target paper for this study. We selected papers by having repeated discussions among several cancer nursing researchers.

2. Data Analysis

(1) Obtaining Data

We conducted an analysis of all of the selected papers via a review sheet that was created using Cooper’s methodology (Cooper, 1998). In order to provide an overview of the targeted texts, the review sheet included the text ID, aim, research design (classified according to Diers (1998), methods, central theme, summary of research participants, and results.

(2) Analytical Methods

For items other than the research content described on the review sheet, we performed simple aggregation using Microsoft Excel 2010.

For the research details, we determined whether there was a focus on the problems of young women with breast cancer as a central theme by perusing each paper. The central theme was used to classify each selected paper.

(3) Ensuring the Reliability of the Analysis

We ensured the reliability of the review sheet classifications by having repeated discussions among multiple cancer nursing researchers.

3. Ethical Considerations

Although this study targeted papers that had been previously published in academic journals, we took measures to protect the privacy of the research participants in the selected-studies and the rights of the initial researchers.

Results

1. Summary of the Literature

Fifty-four English papers were extracted as a result of the initial search. From these, we excluded informational content, conference proceedings, and commentaries, and excluded only academic papers that were available in print. After we read through the titles, keywords, and abstracts of each research paper, 14 papers were chosen for analysis (Table 1). Seven

Table 1 Summary of the 14 papers of nursing related to young women with breast cancer

Item	Group	Number of Papers (%)
Paper's year of publication	2000	1 (7.1)
	2001	1 (7.1)
	2006	3 (21.5)
	2008	2 (14.3)
	2009	2 (14.3)
	2010	1 (7.1)
	2012	2 (14.3)
	2014	2 (14.3)
	Total	14 (100.0)
Country of institution to which authors were affiliated	United States of America	6 (42.9)
	Australia	3 (21.4)
	Canada	2 (14.3)
	United Kingdom	2 (14.3)
	Sweden	1 (7.1)
	Total	14 (100.0)
Study design	Descriptive exploratory research	11 (78.6)
	Correlation research	3 (21.4)
	Total	14 (100.0)
Age of participants	Under 50 years old	5 (35.8)
	Under 45 years old	3 (21.4)
	Under 40 years old	3 (21.4)
	Others	3 (21.4)
	Total	14 (100.0)

papers from the Japanese literature published between 2000 and 2014 were also found by using the keywords “breast cancer”, “young women”, and “nursing” or “care” in Japanese. Of these, we identified no papers that were original research papers, that were written in the correct academic format, and that discussed the nursing care of young women with breast cancer.

(1) Paper Publication Period

The publication years were as follows ; 2000 (one paper), 2001 (one paper), 2006 (three papers), 2008 (two papers), 2009 (two papers), 2010 (one paper), 2012 (two papers), and 2014 (two papers).

(2) Locations of the Authors' Institutions

About 40% of the 14 papers were from the United States; the remaining papers were as follows: Australia (three), Canada (two), the United Kingdom (two), and Sweden (one).

(3) Study Design

Eleven studies were descriptive exploratory research and three were correlational investigations.

(4) Research Participants

Five studies targeted breast cancer patients under 50 years of age and the others had selection criteria of under 45 and 40 years of age, among others.

The remaining studies did not specify the age in the inclusion criteria, but instead specified that the research was intended for young women. The age of the participants in these studies was under 45 or 50 years.

2. Research Contents

We reviewed the 14 research papers using the review sheet, and found that they generally covered four areas: sexual and reproductive health, cancer experience, the role of the family, and rehabilitation needs (Table 2).

The following is a summary of research in each area.

(1) Sexual and Reproductive Health

Of the 14 papers selected for this study, six were research on sexuality and reproduction.

Knobf (2001) investigated how patients recognized and self-managed menopausal symptoms in situations where breast cancer treatment had caused premature menopause. In this study, most participants had experienced menopausal symptoms and having breast cancer had influenced the women's reactions toward their symptoms and their decision-making

Table 2 Summary of the Central Theme

Central Theme	Title	Author	Publication Year
Sexual and Reproductive Health	The Menopausal Symptom Experience in Young Mid-life Women With Breast Cancer	M.T. Knobf	2001
	Young Female Breast Cancer Survivors : Their Sexual Function and Interest in Sexual Enhancement Products and Services	D. Herbenick, M. Reece, A. Hollub, et al.	2008
	A Qualitative Analysis of Reproductive Issues Raised by Young Australian Women with Breast Cancer	S. Connell, C. Patterson, B. Newman	2006
	Young childless women with breast cancer in the UK: a qualitative study of their fertility-related experiences, options, and the information given by health professionals	Corney RH, Swinglehurst AJ	2014
	Development of the Fertility and Cancer Project : An Internet Approach to Help Young Cancer Survivors	K. Meneses, P. McNeese, A. Azuero, A. Jukkala	2010
	Being Young, Female, and BRCA Positive	R. Hamilton	2012
Cancer Experience	Young Women's Experiences with Breast Cancer : An Imperative for Tailored Information and Support	Margaret I, Fitch R. E, Gray R, et al.	2008
	Living the experience of breast cancer treatment : The younger women's perspective	Coyne E, Borbasi S	2009
	Quality of Life, Survivorship, and Psychosocial Adjustment of Young Women With Breast Cancer After Breast-Conserving Surgery and Radiation Therapy	K.H. Dow, P. Lafferty	2000
	Early Adulthood Uprooted : Transitoriness in Young Women With Breast Cancer	M. Shaha, S. Bauer-Wu	2009
	The stressors and vulnerabilities of young single childless women with breast cancer : A qualitative study	Roslyn C, Shuby P, Jane S	2014
The Role of the Family	Transforming Desolation Into Consolation : Being a Mother with Life-Threatening Breast Cancer	J. Ohlen, A. K. Holm	2006
	Holding It All Together : Breast Cancer and its Impact on Life for Younger Women	E. Coyne, S. Borbasi	2006
Rehabilitation Needs	Rehabilitation after Breast Cancer : Recommendations from Young Survivors	J. Easley, B. Miedema	2012

regarding symptom management.

A study involving a sexual function assessment and needs for sexual enhancement products (Herbenick, 2008) administered a questionnaire survey to breast cancer patients under 50 years of age at the time of diagnosis. Most patients had problems related to partner relationships and sexual functioning, such as sexual enjoyment. The women were interested in sexual enhancement products, and the study indicated a need to provide them with information on this topic.

In addition, various aspects about the fertility of young women with breast cancer were covered in the research. For problems and needs concerning reproduction, one study (Connell, 2006) conducted interviews with breast cancer patients under 40 years of age at the time of diagnosis. The authors found that contraception issues were a problem, as there was a fear of breast cancer recurrence due to pregnancy and

breastfeeding. In particular, difficult decisions had been made about unplanned pregnancy and childbirth. They indicated that in order for young women with breast cancer to be satisfied with their decision-making, they had to receive specialized medical support and information. Corney et al. (2014) conducted interviews that focused on information about fertility experiences and options. For many patients, whether fertility can be maintained, the effect of pregnancy on relapse and the child's health were important considerations. However, it was revealed that little information and support was provided regarding these issues.

Meneses et al. (2010) provided information about fertility situation and evaluated the methods of obtaining information for this topic. A questionnaire survey was conducted via the Internet with young women with breast cancer. While participants in this study did use the Internet to acquire information, it was difficult for

them to obtain satisfactory information in this manner. Since general knowledge about reproduction and fertility can be easily obtained, it will be necessary to provide more detailed, specific information about topics such as reproductive technologies and adoption to women with breast cancer.

Another study examined the psychosocial effects on marriage and childbirth (Hamilton, 2012). Phone and e-mail interviews revealed that the goals of women suffering from breast cancer and women with the breast cancer susceptibility gene (BRCA) mutation related to having children. The aim of the women who already had a child was to stay alive for their children; the aim of those with no children was to have a child soon. The study reported that many patients with BRCA mutations told their partner about their breast cancer risks, and struggled with the concept of a prophylactic mastectomy.

(2) Cancer Experience

Research on the cancer experience clarified what young women with breast cancer have experienced by being afflicted with cancer, including the changes caused by cancer.

One study on the experiences and perspectives of women suffering from breast cancer (Margret, 2008) reported that young women with breast cancer had the same perspectives as older breast cancer patients. However, they were also focused on concerns regarding their young families, their work, and their careers. This perspective was closely related to, and had an effect on, their daily lives. Coyne et al. (2009) clarified the experience of young women with breast cancer from the perspective of the cancer treatment experience. Although the side effects of cancer treatment may be very difficult for the women, they tried to deal with these problems positively to live. However, they were too young to take on the "sick role", found it difficult to prepare for the sudden initiation of treatment, and had an insufficient support network for this situation.

One study (Dow, 2000) used a questionnaire survey to statistically analyze how young breast cancer patients' QOL, psychosocial adjustment, and survivorship changed from the start of radiation therapy, through the treatment midpoint, treatment end, and at

six months after treatment.

The results indicated that patients had to adjust their lives in order to respond to the radiation therapy. However, their QOLs decreased from the treatment's commencement to 6 months after treatment. The quality of their social and sexual lives had decreased from radiotherapy initiation until 6 months after treatment. Negative recognitions regarding recognition to survivorship and anxiety to cancer increased from the start of treatment to 6 months after treatment.

Another study examining the effect of breast cancer on the experience of transience and daily life (Shaha, 2009) reported that despite the youth of the patients, they thought about their disease and treatment concerns, their own mortality (fatality rates), their children and partners, family matters, and their careers and work environments. This indicated that even with early stage and early-onset cancer, "transience" was a significant aspect of the cancer experience and support was necessary.

In addition, this study (Roslyn, 2014) revealed the stressors and vulnerability surrounding "concerns about fertility", "partners" and "emotional and realistic support" in a sample of young single childless women with breast cancer. They were concerned about facing the treatment alone, and had anxiety about their possibilities for marriage and pregnancy, as well as whether they would receive any emotional support. The research stated that it was necessary for nurses to individually support such patients.

(3) The Role of the Family

This research focused on the patient's role as a mother and on the impact of the disease on her family members.

For instance, Ohlen et al. (2006) investigated the experience of mothers with breast cancer who had dependent children. The study focused on the transformation of feelings from desolation to consolation. During their involvement with their children, the patients alternated between these feelings and complained about a lack of childcare support to maintain the parent-child relationship. This suggested that relationships with partners, family, and peers should be important considerations when devising measures to

promote the psychological recovery and healing of women with breast cancer.

In addition, a study on the experiences of the breast cancer patients that focused on the impact of the cancer on family and social situations (Coyne, 2006) showed that young women faced a harsher reality compared to breast cancer patients of other age groups. The researchers concluded that this occurred because the younger women played an important role in making other people happy, in terms of family and daily life stability, their reproductive capabilities, and having a family.

(4) Rehabilitation Needs

Easley et al. (2012) conducted an interview survey on the needs, preferences, and recommendations of rehabilitation for patients diagnosed with breast cancer between 18 and 49 years of age. They stated that cancer rehabilitation had become more important as the survival rate increased. Rehabilitation had an increasingly important role, particularly among young women with breast cancer and a low QOL who faced physical, psychological, and social problems. The patient recommendations included “improved communication among the various healthcare professionals”, “healthcare professionals taking a more proactive approach in recommending rehabilitation after treatment”, “better insurance coverage or financial assistance for rehabilitation services” and “more rehabilitation support for rural populations”. The study reported that to provide proper support and post-treatment care, rehabilitation nurses could play an important role in educating patients, recognizing long-term prognoses, and helping patients be actively involved with various healthcare professionals.

Discussion

1. Trends in Research

(1) Paper Publication Period

Only 54 papers were found in the keyword search for “breast cancer”, “young women”, and “nursing” or “care”. The low number of papers may be due to the small percentage of breast cancer patients younger than 35 years old. The percentage of those patients is 2.0% of the total breast cancer population in Japan (Mat-

suda, 2013), while in the United States, the percentage is 1.8% (National Cancer Institute’s Surveillance, Epidemiology, and End Results Program). Therefore, opportunities for nurses to care for young women with breast cancer have been extremely limited. Although nurses can speculate on the problems of young women with breast cancer, we can presume that the reality of the situation is not fully understood since there has not been enough research performed. The small number of papers that were found demonstrated that research on young women with breast cancer remains in its infancy.

(2) Locations of the Authors’ Institutions

Looking at the age-adjusted incidence rate of breast cancer by country, there was a significant number of breast cancer patients in North America, Western Europe, and Australia, and the age-adjusted incidence rate in America has remained the highest in the world since 1980 (Sobue, 2012). Since approximately 40% of the papers in this study were written by researchers in the United States, we can infer a heightened interest in breast cancer in this country due to its high incidence rate.

(3) Study Design

A total of 11 out of the 14 papers selected for this study utilized descriptive exploratory research, which examined the participants’ actual grasp of the situation and their problems. Since there were many studies using this design, it can be presumed that researchers are working on the process of understanding young women with breast cancer. Their situation will be clearer in the future. Many previous studies have highlighted the scarcity of correlation studies in the field of cancer nursing (Makabe, 2013) and a more active approach toward these studies is needed. In the present study, most of the papers targeting young women with breast cancer were Level I or Level II (Diers, 1998) studies illuminating the phenomena that were previously not well understood (what was occurring and why). These were foundational components in the initial development of this research. In the future, we can expect descriptive exploratory research to serve as the foundation for providing evidence for nursing support methods.

(4) Research Participants

In Japan, the phrase “young women with breast cancer” has generally been used to describe women under 35 years of age. However, one study from England (Lee, 2011) referred to women under 40 years of age as young women, and one study in Turkey (Aksoy, 2000) referred to premenopausal women under 50 years of age as young women; therefore, there appears to be great variation in the concept of “young women”. Although the present study also used the term “young women”, we found only a slight difference in the participants’ ages. This may be due to differences in the age groups of cancer patients from each country and differences in the studies’ aims.

The Young Survival Coalition an international organization founded in 1998 for young women with breast cancer, targets breast cancer patients in their 20s and 30s. The survival rate of breast cancer patients under the age of 40 are lower than that of breast cancer patients over 40 years old, and these patients face various serious problems, such as reproductive/fertility problems affecting early menopause and pregnancy, job and career advancement difficulties, and financial difficulties (young survival coalition). As a result, the organization states that specific support is necessary. Due to changes in the social advancement of women, the average age at first marriage, average age of first childbirth, and the societal changes in the treatment development, the definition of “young women” may fluctuate in the future. However, if we accept that young women face a harsh reality precisely because they are young, then it is imperative to gain an accurate understanding of this phenomenon and determine appropriate support methods.

(5) Research Contents

The central themes of the literature chosen for analysis were classified into research on sexual and reproductive health, cancer experience, the role of the family, and rehabilitation needs.

The majority of the research focused on the problem of sexual and reproductive health for young women with breast cancer. In the papers targeted in this study, “young women” with breast cancer referred to those roughly under 40 years of age, which is an age of

active ovarian function and increased fertility (Yoshizawa, 2010). In other words, many women experience major life events during this period, such as pregnancy and childbirth; therefore, women diagnosed with breast cancer who receive treatment during this period can face concerns about their future sexual functioning and reproductive capabilities. They may be torn between “becoming a mother” and “living/staying alive”. This phenomenon is a serious problem that arises precisely because they are young women with breast cancer. How healthcare professionals treat this distress is a pressing issue that needs evaluation. Attempts to clarify the current situation of young women with breast cancer, such as the sexual and reproductive issues (Corney, 2011) and the patients’ needs (Cornell, 2006) that were mentioned in this study, will serve as important initiatives for investigating future care directions.

Research that focused on the impact on thoughts and lifestyle investigated the effects that being diagnosed with breast cancer at a young age and cancer treatment had on patients’ perspectives and their outlook on life. These studies found that because the patients were young, they thought a great deal about their children, spouses, and personal careers, and tried to reconstruct their lives by adjusting their previously held lifestyles and perspectives. At this time in their lives, they were restrained from life events, such as marriage and childbirth, but were also expanding their societal roles and building their work and careers. It was a great shock for these young women to face a breast cancer diagnosis and treatment in the midst of designing their own life plan, and the planned image of their future was changed. In order to recover from this shock and begin moving toward a new existence with cancer, it would be essential to transform their outlook and adjust their lifestyles. Thus, the changes in these young women’s thoughts and lifestyles can also shed light on how they face cancer and cancer treatment. Determining whether they found a way to live with cancer could be important for understanding the reality of young women with breast cancer.

Other research on the role of the patient and family investigated the experiences of young women with

breast cancer from the perspective of their maternal and family roles. These studies indicated that breast cancer and its treatment greatly affected these roles and that there was a need for support to maintain them. As stated earlier, patients who were “young women” were not just single women; they included mothers who gave birth and raised children, wives who supported husbands and managed household duties, and working professionals. When women of this age were diagnosed with breast cancer and received long-term treatment, it not only changed the women’s own roles, but also caused restructuring in their family and societal roles, such as in the workplace. If such roles create feelings of usefulness and self-efficacy, and maintain and increase self-worth, then it will be important in the future to provide support so they can maintain and fulfill their roles, and retain their self-esteem and self-worth.

Research on rehabilitation needs evaluated these in terms of the young women’s rehabilitation preferences. Compared to other cancers, the five-year survival rate for breast cancer is high (Sobue, 2012), and young women with breast cancer in particular will generally live as cancer survivors for a long time. In order for young women who experienced physical and psychological obstacles from cancer and its treatment to return to their regular lives, it is important for them to have a smooth recovery and to maintain and improve their remaining activities. Given that it has become possible to significantly shorten the length of hospital stays after breast cancer surgery, cancer rehabilitation fulfills a significant role as a means of social rehabilitation. In recent years, the need for cancer rehabilitation has been shown in many Japanese papers (Tsuji, 2005; Hayakawa, 2012), and cancer rehabilitation fees have been factored into the 2010 revision of medical treatment fees (Ministry of Health, Labour and Welfare). We hope that in the future, there will be continued research on effective cancer rehabilitation methods and their results. In the study of Easley et al. (2012), patients made recommendations regarding the communication continuity between the healthcare team members and patients, as well as a more active approach toward rehabilitation from healthcare professionals.

Future studies are needed to investigate nurses’ roles as members of the rehabilitation healthcare teams and the necessary support.

2. Issues in Research on Nursing for Young Women with Breast Cancer

Previous research has noted that, compared to other age groups, young women with breast cancer faced numerous problems and required significant support. However, we found little research on this patient group in the existing literature, as this area was still in its infancy. We need to promote basic research to construct theory and knowledge on nursing for young women with breast cancer, and to establish evidence-based nursing interventions.

Furthermore, current research on young women with breast cancer focuses primarily on the individual aspects of these women’s problems: sexual and reproductive health, cancer experience, the role of the family, and rehabilitation needs. However, when considering nursing support for young women with breast cancer from a holistic viewpoint, it is important for nursing practices to be based on their comprehensive experiences while they deal with cancer and receive treatment. Therefore, to obtain a complete picture of young women with breast cancer, future studies should approach the issue from physical, psychological, and social perspectives.

Conclusion

This study was an overview of non-Japanese research on nursing for young women with breast cancer. However, it had certain limitations. First, in recent years, the term “young women with breast cancer” has come to include not only young women, but also adolescents and young adults; these age groups should be the focused of further study. This study’s targeted literature also did not include research featuring comparisons based on age, so we cannot rule out the possibility that these studies did mention nursing for younger patients with breast cancer. As such, it was difficult to call this an exhaustive review of all literature targeting young women with breast cancer.

Additionally, while this literature review was performed carefully by multiple researchers, the conclusions were still subject to bias as they might have been influenced by subjective judgments. Further research could address these study limitations.

This study found that research on nursing for young women with breast cancer was still in its infancy. We expect that, in the future, foundational research on young women with breast cancer will be undertaken, not only overseas, but in Japan as well, and that there will be active efforts to create nursing support methods for these young women.

Acknowledgment

This work was supported by JSPS KAKENHI Grant Number 32309.

No potential conflicts of interest were disclosed.

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若年性乳がん患者の看護に関する研究の動向と今後の課題

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要 旨

目 的：本研究の目的は、若年性乳がん患者の看護に関する国内外の研究論文の動向と課題を明らかにすることである。**方法：**若年性乳がん患者の看護について述べている論文を抽出するため、CINAHL 及び Web 版医学中央雑誌 Ver. 4 を使用し、「breast cancer (乳がん)」「young women (若年女性)」「nursing (看護)」または「care (ケア)」をキーワードに検索を行った。**結 果：**14 件の論文が分析対象となり、研究内容は、性・生殖に関する研究、がん罹患体験に関する研究、家族における役割に関する研究、リハビリテーションの必要性に関する研究に大別された。**考 察：**若年性乳がん患者に関する研究は少なく、着手されたばかりの萌芽期にあることが明らかとなった。海外諸国のみならず、我が国においても若年性乳がん患者の看護に関する基礎的な研究を積み重ね、看護支援方法の構築に向けた積極的な取り組みが期待される。

キーワード：若年女性，乳がん，看護，文献レビュー

