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# Original Article

# A hermeneutic phenomenological study on the disease experience among young women with breast cancer



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#### ABSTRACT

Objective: Women diagnosed with breast cancer under the age of 40 face distinctive physical and psychosocial challenges resulting from the disease's pathological features and the developmental aspects associated with their youth. This study aims to investigate the lived experience of breast cancer among this group of young women. *Methods:* Participants were purposefully selected from online communities and chat rooms in South Korea. A total of 15 young women with breast cancer were included in this study, and data were gathered through three focus group interviews. The interviews were transcribed verbatim and analyzed using the hermeneutic phenomenology method

Results: Four essential themes emerged based on four lifeworld existentials: lived body, lived time, lived space, and lived others. These four essential themes were: a wounded and sick body, life robbed of youth and elderly years, crossroads of growth discovered at life's extremes, and a steadfast companion on a solitary journey. Conclusions: Young women with breast cancer face unique challenges due to the intersection of a severe illness and its impact during their formative years. This study offers valuable insights for crafting customized interventions that directly target the physical and psychosocial requirements of young breast cancer survivors, ultimately enhancing their quality of life.

# Introduction

Breast cancer is the most common cancer among women worldwide, <sup>1,2</sup> and its incidence continues to increase yearly. <sup>3</sup> Generally, breast cancer occurs in women over the age of 50. <sup>3</sup> However, the incidence rate among young women under the age of 40 constitutes approximately 4% of all cases, with one out of every 65 women being diagnosed with breast cancer before the age of 40. <sup>4</sup> In other words, the population of young women under 40 with breast cancer is consistently growing, emphasizing the need to focus on this group. In Korea, where this study was conducted, the proportion of premenopausal patients with breast cancer is approximately 10.5%, significantly higher than that in Western countries. <sup>5</sup> Breast cancer treatment outcomes have improved <sup>6</sup>; nevertheless, a high survival rate does not necessarily guarantee a high quality of life for survivors. Therefore, special attention should be paid to young women with breast cancer, considering their extended lives as cancer survivors.

Young women under the age of 40 have a poorer prognosis compared to women in their 40s and 50s, with significantly lower overall and breast cancer-specific survival rates, <sup>7</sup> and show an increased risk of hereditary

breast cancer.<sup>4</sup> Owing to these pathological characteristics, aggressive treatments are recommended, which lead to drastic physical changes both in appearance and function, such as breast deformation,<sup>8</sup> early menopause, and decreased fertility.<sup>9</sup> Standard treatment extends for up to 10 years after the completion of active treatment, depending on the cancer type, and continuous follow-up is necessary throughout long-term survivorships.<sup>10</sup> Furthermore, psychosocial distress is compounded for young women who have developmental tasks such as marriage and childbearing, and are undergoing social transitions in education and careers.<sup>11</sup>

The European School of Oncology (ESO) and the European Society of Medical Oncology (ESMO) define "young women" with breast cancer as women under the age of 40 at the time of diagnosis and emphasize the importance of providing psychosocial support to this population. <sup>4</sup> In this context, various studies have been conducted to identify the unique psychosocial challenges faced by young women with breast cancer. Several studies have shown that young patients with breast cancer perceive a greater risk of cancer recurrence, <sup>12</sup> experience higher levels of depression and anxiety, <sup>13</sup> and have significant psychosocial needs related to their work, education, finances, fertility, and social relationships. <sup>13,14</sup>

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A study conducted in Korea found that young breast cancer survivors experience lower psychosocial adjustment than older survivors. <sup>15</sup> Other studies identified the impact of uncertainty on their quality of life <sup>16</sup> and factors contributing to the spousal caregiving burden. <sup>17</sup> However, these studies categorized the age group using a general criterion of 50 years based on a broad distinction between young and old, or the average age of natural menopause. The pathologic characteristics of breast cancer vary at the age of 40. Additionally, the experiences of those in their 20s and 30s exploring life's directions differ significantly in terms of social and developmental tasks from those in their 40s with established foundations in their families and careers. Therefore, existing research has limitations in understanding the disease experiences of young women with breast cancer. Since Korea has a higher proportion of this population, efforts to comprehend their unique experiences are necessary.

Given that psychosocial responses to breast cancer vary across cultures, illness experience of breast cancer among young Korean women should be examined within the sociocultural context of Korea. Therefore, this study aimed to explore the essential meaning of the disease experience of young women with breast cancer using van Manen's hermeneutic phenomenological method. Hermeneutic phenomenology involves an in-depth exploration of participants' experiences and the analysis of diverse sources reflecting the sociocultural and historical context. This approach will provide insight into and a richer understanding of the phenomenon of interest. Additionally, this study will lay the foundation for developing interventions that provide physical, psychological, and social support to young women with breast cancer.

#### Methods

#### Design

This qualitative research employed van Manen's hermeneutic phenomenological approach  $^{18}$  to comprehensively understand the meaning and essence of the disease experience of young women with breast cancer.

# Participants and setting

Based on the definitions of "young women" by the ESO and ESMO, this study focused on women under the age of 40. To ensure voluntary consent, women aged 18 or older were recruited. Therefore, this study targeted women aged 18 to under 40 with breast cancer. This age group represents a younger demographic compared to the predominant age group among breast cancer patients (over the age of 50). It also aligns with the concept of "youth," a time of youthfulness and vitality in one's life, in the sociocultural context of Korea.

The participants in this study were women with breast cancer who had completed active treatment (surgery, chemotherapy, and radiotherapy). Additionally, we selected women with good general health and no evidence of further metastasis or recurrence to minimize the physical burden of participating in the study and ensure that they focused on the nature of their disease experience. Purposive sampling was employed, and participants were recruited from online communities and chatrooms dedicated to facilitating peer support among breast cancer patients and their families.

With the cooperation of group managers, we posted a recruitment document summarizing the study's purpose, methods, and eligibility requirements. Participants who were interested in participating contacted the researchers directly and were assessed to ensure they met the inclusion criteria. A total of 19 women volunteered to participate. Since one of them was over the age of 40, 18 women met the eligibility requirements.

# Focus group organization

Focus group interviews (FGIs) are an effective strategy for obtaining broader insights and gaining in-depth understanding through

interactions among research participants sharing their experiences on specific topics. <sup>19</sup> This study employed FGIs because they allow young women with breast cancer—a minority among breast cancer survivors—to maximize their voices and bring their unique struggles to the forefront in a comfortable peer environment. Krueger and Casey suggest an ideal group size of five to eight participants and that the number of interview sessions should range from three to four for a nonprofit FGI. <sup>19</sup> Accordingly, we organized three groups of six participants each.

To facilitate relatable discussions in a comfortable and intimate environment, participants were categorized into groups with similar characteristics: those with a relatively short (Group 1 and Group 2) or long (Group 3) time since diagnosis. One participant from each group dropped out because of personal reasons, resulting in three FGIs with five participants each and a total of 15 participants.

# Data collection

# Experiential descriptions from literature and art

To deepen our phenomenological insight, we examined experiential descriptions regarding the disease experience of young women with breast cancer portrayed in literature and art. We referenced Nina Riggs' essay "The Bright Hour: A Memoir of Living and Dying," which depicts her battle with breast cancer in her 30s and subsequent passing. We also referenced Guido Reni's painting "The Death of Cleopatra," which illuminates the beauty and symbolism attached to women's breasts. Through these valuable sources, we aimed to enhance our comprehension and sensitivity to the participants' experiences.

### In-depth exploration of participants' experiences

The data were collected in March 2023. To ensure the safety of both participants and researchers amid the COVID-19 pandemic and enhance the ease of participation, data were collected through video interviews using Zoom, which is widely used in Korea. Semi-structured interview questions were developed during three research meetings by incorporating insights from existing literature on young women with breast cancer<sup>14,22,23</sup> and the researchers' inquiries (Table 1). During the interviews, all participants turned on their cameras, making their faces and upper bodies visible and allowing for the observation of nonverbal cues such as body language.

The first author, who had expertise in breast cancer nursing and qualitative research and was of the same age and gender as the participants, conducted the interviews in a safe and familiar atmosphere. The corresponding author provided assistance and took field notes. Each group underwent one FGI session, which lasted approximately 2 hours. Upon reviewing the interview transcripts, all researchers agreed that theoretical saturation had been reached and ended the interview process.

**Table 1** Overview of the interview questions.

Type of question	Questions		
Opening question	Can you please introduce yourself briefly?		
Introductory question	What has your journey been like since your breast cancer diagnosis?		
Transition question	What was your biggest concern when you were		
	diagnosed with breast cancer?		
Key questions	What changes have you noticed in your body since		
	being diagnosed with breast cancer?		
	How has your life changed since being diagnosed		
	with breast cancer?		
	Were there any specific challenges that were more		
	pronounced because you were diagnosed with		
	breast cancer at a young age?		
	How do you communicate with others about these		
	life changes and concerns?		
Closing question	Is there anything else you would like to add?		

#### Data analysis

The data were analyzed using van Manen's hermeneutic phenomenological research method. 18 First, two researchers read the transcripts multiple times to understand the overall meaning. Next, words, sentences, and paragraphs were examined one by one, and significant texts were identified and categorized based on their concept, context, and relationships. At this stage, hermeneutic reduction was applied, which refers to the process of extracting essential meaning from complex phenomena to interpret and understand them. More specifically, we derived fundamental themes that captured participants' experiences. Third, the categorized texts were classified into themes to structure the meaning of participants' lived experiences. These themes were organized into essential themes based on four lifeworld existentials: lived body, lived time, lived space, and lived others. Furthermore, we examined how the meanings revealed in literature and art were related to participants' narratives and incorporated them into deriving themes and describing the phenomenon.

The first author conducted the primary data analysis, and all researchers reviewed and refined the data through three research meetings to finalize the analysis results.

## Research rigor

This study secured research rigor based on the criteria of truth value, applicability, consistency, and neutrality. <sup>24</sup> First, to ensure truth value, participants who could describe the research phenomena were purposefully selected and encouraged to express their experiences freely. After data analysis, three participants, one per group, confirmed whether the findings accurately reflected their experiences. Second, to enhance applicability, participants' general and disease-related characteristics were presented. Third, to establish consistency, data were analyzed according to van Manen's research method, <sup>18</sup> and the entire research process was described in detail. Fourth, to ensure neutrality, the researchers made efforts to maintain a neutral standpoint and analyzed the data from the participants' perspectives as much as possible. The research outcomes were validated by two external qualitative researchers with breast cancer nursing experience to minimize potential researcher biases.

## Results

A total of 15 young women with breast cancer participated in this study. Their age ranged from 26 to 39 years, with a mean age of 33.9 years; most were married (66.7%). Four participants had one child before being diagnosed with breast cancer, and the rest had no children. Most participants (73.3%) were employed; some of them were on disease leave

or temporarily employed. The time since breast cancer diagnosis ranged from one to seven years, with a median of two years. Six participants had stage I, eight had stage II, and one had stage III breast cancer. They received various treatments, including surgery, chemotherapy, radiotherapy, hormone therapy, and targeted therapy, depending on their cancer type (Table 2).

#### Hermeneutic phenomenological reflection

After analyzing the data using van Manen's hermeneutic phenomenological approach. <sup>18</sup> Ten themes and four essential themes were derived based on four existential dimensions (Table 3).

Lived body: wounded and sick body

Disfigured body with diminished femininity. The loss of the breast, which is believed to symbolize sensuality and the source of life, resulted in grief tantamount to the loss of womanhood for the participants. Changes in their physical appearance that they could not hide, such as a lumpy and swollen body and thinning hair due to treatment, felt like the mark of a patient with breast cancer. The loss of menstruation, which was once considered an unwelcome visitor every month, and the diminished fertility that hindered their reproductive function made them lose self-confidence. Feeling disfigured in terms of both attractiveness and function as a woman because of the "shameful cancer," the participants became conscious of others' gazes and experienced a sense of diminished self-worth.

When I had my first consultation, the doctor told me that I must undergo a mastectomy and described how they would cut my breast. At that time, I

**Table 3**The lived experience of young women with breast cancer.

Existential dimensions	Essential themes	Themes
Lived body	Wounded and sick body	Disfigured body with diminished femininity Unhealthy and damaged body
Lived time	Life robbed of youth and elderly years	Skipping youth and arriving at middle age Uncertain and distant future of old age
Lived space	Crossroads of growth discovered at life's extremes	Lost milestones of life Daily life bound by various constraints Embracing life's turning point
Lived others	Steadfast companion on a solitary journey	Suffering alone without authentic empathy Youth as an additional stigma Healing through the connection with peers

**Table 2**General and disease-related characteristics of the participants.

Group	No.	Age (years)	Marital status	Child status	Employment	Time since diagnosis (year)	Cancer stage	Treatment history
G1	P1	32	Single	Does not have	Employed	1	I	OP, CTx, RTx, HTx
G1	P2	37	Married	Has	Employed	2	II	OP, CTx, RTx, HTx
G1	Р3	34	Married	Does not have	Employed	1	I	OP, CTx, RTx, HTx
G1	P4	33	Single	Does not have	Employed	1	II	OP, RTx, HTx
G1	P5	29	Married	Does not have	Unemployed	1	II	OP, CTx, RTx
G2	P1	34	Married	Does not have	Unemployed	3	II	OP, CTx, RTx
G2	P2	26	Single	Does not have	Employed	2	II	OP, CTx, RTx, HTx
G2	Р3	32	Married	Has	Unemployed	1	I	OP, HTx
G2	P4	32	Single	Does not have	Employed	1	I	OP, CTx, RTx, HTx
G2	P5	38	Married	Has	Employed	2	II	OP, CTx, RTx, HTx
G3	P1	38	Single	Does not have	Employed	6	II	OP, CTx, RTx
G3	P2	39	Married	Does not have	Employed	7	I	OP, CTx, HTx, TTx
G3	Р3	34	Married	Does not have	Employed	2	III	OP, CTx, RTx, TTx, HTx
G3	P4	32	Married	Does not have	Employed	6	II	OP, CTx, RTx, HTx
G3	P5	39	Married	Has	Unemployed	6	I	OP, CTx, RTx

CTx, chemotherapy; G, group; HTx, hormone therapy; OP, operation; P, participant; RTx, radiotherapy; TTx, targeted therapy.

was still unmarried, and the thought of losing my breasts was the most overwhelming concern for me. (G3, P2)

After receiving treatment and no longer menstruating, I often thought, "My life as a woman is over." I had many worries about the limitations of my sexual relationship with my husband. (G1, P2)

Unhealthy and damaged body. After undergoing breast cancer treatment, participants experienced various physical changes and symptoms. They frequently endured surgical site pain and unfamiliar sensations that caused continual discomfort. Following an axillary lymph node dissection, raising an arm or performing even simple exercises became challenging, and some participants suffered from swelling and pain that did not improve even with repeated rehabilitation. Those who underwent breast reconstruction using autologous tissues from their abdomen, back, or thighs found it difficult to maintain proper posture because of a pulling sensation in the donor sites. Their physical stamina, which had drastically reduced during breast cancer treatment, could not be fully recovered over time, leaving them feeling heavy and fatigued all the time.

My arms have about a 1-2 cm difference in thickness between them. Whenever I lift something heavy or my health condition is not good, this asymmetry becomes more noticeable, leading to discomfort and limitations in my daily life. (G2, P1)

I had a lot of cancerous breast tissue removed, and the breast was reconstructed using back muscles and latissimus dorsi. Now, I have scoliosis because one side of my back lacks muscles, but I also experience pain on the other side of my back. I also suffer from some discomfort in my waist. The pain continues to bother me. (G3, P1)

Lived time: life robbed of youth and elderly years

Skipping youth and arriving at middle-age. Breast cancer, which unexpectedly struck during their youthful years, robbed participants of their youthfulness and vitality. Their dry and flaky skin, mottled freckles, and thinning, sparse hair resembled those of middle-aged women. They felt as if they had borne the brunt of time alone because of their rapidly aging appearance. With declining physical strength and weakened joints, even keeping up with friends while walking felt like an uphill battle. Menopause induced by hormone therapy caused unexpected symptoms such as hot flashes, similar to what menopausal women experience. Owing to the inconsistency between their biological and chronological age, the participants felt as if they had been transformed into middle-aged bodies at a young age, and they expressed a sense of solidarity with those in their 50s and 60s rather than with their peers.

Other people experience menopause, declining estrogen, or other issues that gradually come with aging, but we're experiencing all these side effects at once, something that people our age wouldn't normally experience. (G1, P4)

I'm currently undergoing hormone therapy, and my joints are really bad. I'm living in a duplex now, but my legs are so weak that I end up going down the stairs using my hips instead of my legs. I feel like I've become so weak compared to my age, and it's been really tough for me. (G2, P2)

Uncertain and distant future of old age. For participants who found it difficult to contemplate death at such a young age, it was even more challenging to envision their future five or ten years ahead. Breast cancer, notoriously known as "long-tailed cancer" because of standard treatments that can take up to 10 years and recurrences that are not uncommon even after treatment, was a constant source of fear for the participants. Any slight decline in their health amplified their anxieties and made them wonder whether cancer might return. They had once thought that aging was a natural part of life. However, through this

formidable disease, they were reminded of the fragility of life and the course of nature. Some participants also expressed a vague feeling of wandering alone on the street with a bomb of finite time.

After treatment ended, the doctor said, "You are cured." But another wave of anxiety sets in. "Will I be okay after one year? Two years? Can I safely have a baby? Can I see my child getting married?" I heard cancer can come back in 20 or 30 years, and I worry I'm going to be one of those cases. (G1, P5)

Since my diagnosis, I find myself the most envious of elderly people who have been living healthily without any accidents up until now; it's not something that can be taken for granted. (G1, P5)

Lived space: crossroads of growth discovered at life's extremes

Lost milestones of life. Breast cancer disrupted the lives of participants at a time when they should have been at the peak of their social and economic lives. Participants experienced vocational constraints because of frequent hospital visits for treatment or changes in their physical appearance and function and felt uncertain about what they should do for a living. Some experienced opposition to marriage due to their cancer diagnosis and gave up on marriage altogether. Concerns about impaired fertility due to breast cancer treatment and fears of recurrence made child planning challenging even after marriage. Comparing themselves to peers who were confidently developing their careers and raising children, the gaps in their lives continuously widened, significantly eroding their self-esteem.

It was a time to be active in social activities, earn money, and build a career, but being diagnosed with breast cancer at this crucial point left me wondering, "What can I do for work? How can I make money?" As I'm not yet married, I'm also worried about how cancer would affect my future marriage and childbearing. I can't predict how my potential partner will react to my situation. (G1, P4)

Daily life bound by various constraints. After being diagnosed with breast cancer, participants became hyper-vigilant and cautious about even the simplest daily activities, fearing the impact on their bodies. Even eating regular meals with family and friends became a source of stress and worry, as they constantly questioned whether certain foods were good or bad for their health. This heightened sense of caution led to restrictions on their hobbies, daily routines, and social interactions they once enjoyed. Despite their efforts to ease their minds and not be overly concerned, family members and friends bombarded them with constant advice, telling them, "Don't do this, don't do that." With all the restrictions on them, participants' latitudes were narrowing every day.

After being diagnosed, I tended to worry about all the things, such as "If I eat this, will it cause a recurrence? If I have this, will it lead to metastasis?" (G2, P2)

Pole dancing used to be my hobby, but it involves using my arms a lot. I worried it might cause edema, and reversing that would be difficult. So, I ended up not doing it. Sometimes, I used to go to clubs to relieve stress and enjoy my youth, but now I can't enjoy that anymore because I want to avoid alcohol or cigarette smells. (G2, P4)

Embracing life's turning points. Through their experience with breast cancer, the participants could reflect on their lives. They developed a sense of gratitude even for the small joys they had taken for granted earlier. Facing the inevitability of human mortality, their attitudes toward life became more flexible, and they gained a sense of generosity in approaching everything. Those who had always strived relentlessly for achievements paused their intense lives for a moment, finding joy in the present and realizing the importance of contentment. Breast cancer became a turning point in their lives that made them realize "being

healthy is a success, and this moment is a gift." Based on this realization, they embraced new challenges, prioritized their health, and used the experience as a springboard for their future journeys of growth.

As a result of this illness, I am currently attending graduate school for counseling to help other patients. Cancer became a motivation for new challenges and opportunities in my life. (G3, P3)

When I thought that I didn't know when something might go wrong, I thought, "Why have I been so preoccupied with practical matters and neglected to do things that truly bring joy to me?" This realization motivated me to stop postponing what I wanted to do and be more present in my life. I think it was a turning point when I realized, "I'm just grateful that I'm healthy and alive." (G2, P4)

# Lived others: steadfast companion on a solitary journey

Suffering alone without authentic empathy. Participants expressed the pain of not being fully understood by those who had not experienced the illness including close family members and longtime friends. They felt disappointed and disheartened by the lack of genuine empathy and consideration from others, despite revealing their breast cancer diagnosis. Fake sympathy and clumsy consolation only caused further pain to the participants. People murmuring behind their backs and not offering help made the participants conceal their disease from acquaintances and close family members. Consequently, they had to pretend to be bright and strong while suffering in silence and solitude.

It's disheartening when people around me say, "Breast cancer is a good cancer (treatable and with a good prognosis)." There's no such thing as a good cancer; it's all cancer! I was like, "If it's really good cancer, they should get it." I received insurance settlements, but a friend once said casually, "Wow, that's amazing. I envy you." It hurt me deeply. I don't want millions or billions as compensation for my cancer diagnosis. One person even said, "You deserve cancer." Such remarks were uncomfortable for me. (G2, P2)

Youth as an additional stigma. Owing to their young age, the participants were a noticeable minority among patients with breast cancer. Even during hospital visits for treatment, they felt burdened by the constant uneasy glances from others because of their youth. It became common for them to be pitied solely for being diagnosed with cancer at a young age, even by patients with breast cancer in other age groups. Conversely, the participants were deeply hurt by patients who dismissed their suffering because they were younger despite facing the same life-threatening disease. For the participants, youth became a stigma that distinguished them from other patients with breast cancer.

Just because we're in different age groups, they're talking about me, saying, "Oh, what a pity that this young person got cancer." I don't want to get cancer; I want to be healthy and active at this stage of my life. Hearing such comments makes me annoyed and upset. (G1, P5)

Someone (a patient with breast cancer) said, "Since you're young, you'll be fine; you'll recover quickly. Being young is the best." I felt really uncomfortable with such comments. Many people seem to take my suffering lightly because I'm young. (G2, P2)

Healing through the connection with peers. For participants who had no place to fully express their worries or no one to lean on for support in difficult times, communicating with peers who shared the same pain became the only outlet to ease their stifled emotions. Despite being complete strangers, they naturally formed a strong bond akin to that of a family, knowing they shared similar wounds. The fact that someone walked the arduous journey of illness with them provided immense comfort to the participants. They could empathize with each other's

feelings and exchange heartfelt words of comfort without explaining anything; this alleviated their weary bodies and minds. They navigated through breast cancer treatment and challenges unique to their age, such as dating, marriage, pregnancy, childbirth, and careers, and became each other's companions for the future.

When we get together and chat, it's a great stress reliever, easing our psychological burden and feelings of depression. We can talk about everything, even things our husbands and families may not fully understand; we find comfort in each other and can receive support we can't get from others. (G1, P5)

#### Hermeneutic phenomenological writing

The participants were confronted with sudden and drastic physical changes caused by the unexpected intrusion of breast cancer into their peaceful lives. After having their breasts removed as treatment and experiencing the interruption of their menstrual cycle, the participants lamented about the heart-wrenching feeling of losing their natural feminine appearance and functions as if their womanhood had come to an end. Furthermore, their depleted energy and strength, like a drained battery, accompanied by various physical symptoms, such as pain and swelling, made them feel helpless and distressed.

The weakened joints and aged appearance that did not match their age, along with the menopausal symptoms from induced menopause, left the participants feeling bewildered and in despair, as if they had lost their youth and unexpectedly landed in midlife. Never-ending treatments and the constant fear of recurrence made it difficult for the participants to envision their distant future or even foresee the near future. Breast cancer had taken away their youth and robbed them of hope for their old age.

The participants' strides toward a bright future were hindered by the towering barrier of breast cancer. They lost their compass and drifted aimlessly, leaving behind the life tasks they would have accomplished if not for breast cancer. Their daily lives were completely turned upside down by breast cancer, leaving them confined within a restricted sphere. However, by considering this disease a stepping stone rather than an obstacle to a new leap forward, the participants transformed breast cancer into a turning point instead of an endpoint in their lives.

The participants, rather than seeking empathy and comfort from those who had not experienced the illness, became more accustomed to concealing their true feelings and suffering in silence. As their youthfulness became another stigma that isolated them from even other patients with breast cancer, the participants built stronger walls around their hearts. However, through their bond with peers who shared the same pain, the participants nurtured each other's pain and alleviated the burden they once had to endure alone, strengthening their will to live.

Youth, which is considered a precious stage of life filled with dreams and hopes, became a source of despair and sadness, compounding participants' pain from breast cancer. Despite being diagnosed with breast cancer at a young age, the participants resumed their life journey with new realizations and support from their peers.

# Discussion

This study explored the meaning of disease experience among female breast cancer survivors under the age of 40. Based on van Manen's hermeneutic phenomenological method, <sup>18</sup> four essential themes emerged: wounded and sick body, life robbed of youth and elderly years, crossroads of growth discovered at life's extreme, and steadfast companion on a solitary journey.

Women with breast cancer experience drastic physical changes due to the disease and treatment. Visible changes such as breast removal and alopecia have been reported to disrupt their body image and lead to psychosocial distress. Similarly, the participants of this study perceived physical changes as a marker of being a patient with breast cancer, which reduced their self-confidence. Moreover, due to the decline in their

ovarian function and fertility, the participants experienced the distress of losing both the appearance and function of a woman. The psychosocial distress related to reproductive function in young breast cancer survivors is distinct from that experienced by women after menopause, which mainly centers around breast transformation and constitutes an essential aspect of their bodily experience.

The participants experienced various physical symptoms after breast cancer treatment. Pain, lymphedema, and reduced stamina were identified as representative symptoms that caused continuous discomfort and limited daily activities. For patients with breast cancer, appropriate exercise and stretching can relieve physical symptoms and support daily living, improving arm range of motion, alleviating pain, reducing fatigue, enhancing physical and psychological functions, and thus improving their quality of life. However, many participants in this study restricted their activities or felt limitations in exercising due to concerns about straining their bodies. Therefore, it is important to offer exercise interventions that provide practical guidance and continuous monitoring based on the individual's condition. Simultaneously, multifaceted strategies should be devised that foster acceptance of their altered body and enhance their body image and quality of life. However, and reduced the strategies are supported by the support of their altered body and enhance their body image and quality of life.

Participants experienced rapid aging due to breast cancer treatment; particularly, those undergoing hormone therapy reported the most severe menopausal symptoms. Joint pain, hot flashes, weight gain, mood swings, decreased libido, and vaginal dryness are common side effects of hormone therapy that significantly impair the quality of life of patients with breast cancer. Despite the excellent therapeutic effects of hormone therapy, these side effects cause medication nonadherence and treatment discontinuation among breast cancer survivors. Hormone therapy nonadherence rates are high, especially among young patients who may require long-term treatment for up to 10 years. Based on previous research showing that social support, cooperation with health care professionals, and high self-efficacy improve treatment adherence, support tailored for young women should be provided.

Participants expressed fear and uncertainty about breast cancer recurrence. Young women are more likely to experience fear of recurrence than women in older age groups, <sup>32</sup> leading to severe distress among both cancer survivors and their families. <sup>33</sup> Previous research has identified that effective communication and counseling with healthcare professionals help to manage anxiety and uncertainty about recurrence. <sup>34</sup> Therefore, psychological support and counseling should be offered to young patients with breast cancer and their families. Additionally, providing specialized health care with systematic monitoring can help them better understand their situation, anticipate the future, and detect risks early, which can significantly reduce everyday anxiety.

Participants experienced career interruptions and challenges in marriage and pregnancy because of their social and developmental characteristics. Young patients with cancer without a strong economic foundation may face household financial burdens from medical expenses. A previous study reported that young cancer survivors may initially experience difficulties in making career choices because of their physical and psychosocial changes associated with cancer, but employment improves their overall quality of life. Therefore, practical programs for career development should be provided to alleviate the economic burden and enhance the quality of life of young breast cancer survivors. Particularly in Korea, where the employment rate of women is significantly lower than that of men, T it is crucial to develop essential programs in collaboration with national policies.

With the increased age of first marriage and childbirth, many participants had no specific child planning at the time of their cancer diagnosis. Reduced fertility can negatively impact the psychological health and quality of life of women with breast cancer and result in further social problems, such as changes in family function and decreased birth rates.<sup>38</sup> Recently, various fertility preservation techniques have been developed and included in international oncology guidelines.<sup>39</sup>

Furthermore, prospective studies are being conducted worldwide on the safety of discontinuing hormone therapy for hormone-positive breast cancer to attempt pregnancy. <sup>40</sup> Evidence from these studies will provide practical support for post-cancer pregnancy. Although adoption is not common in Korea, it can be a viable option for breast cancer survivors. Providing guidance about different options and increasing sociocultural awareness are pivotal for facilitating effective family planning.

Despite numerous difficulties, the participants viewed their breast cancer diagnosis as a turning point in their lives. After being diagnosed, they developed a deep appreciation for life, actively managed their health, and embraced new challenges. They considered experiencing breast cancer as an opportunity for growth, even though the degree of this consideration varied. This aligns with the findings of a previous study that found that many women undergo positive growth afterward, which is termed posttraumatic growth. There may be significant differences in patients' quality of life depending on whether they perceive cancer as a traumatic event or an opportunity for growth. Therefore, various interventions should be developed to promote the posttraumatic growth of women with breast cancer.

The participants did not receive sufficient empathy from family and friends who had not experienced the disease and felt marginalized even among other patients with breast cancer because of their young age. This finding is consistent with young women with breast cancer experiencing discomfort amid mixed-age groups, <sup>43</sup> contrary to general beliefs that self-help groups composed of patients with the same disease provide psychosocial support. <sup>44</sup> To address these challenges and fulfill their psychosocial needs, the participants engaged in online chats to communicate, empathize, and encourage peers in their age group. Thus, web-based peer support can be an effective medium for providing psychosocial support to young breast cancer survivors.

## Limitations

This study has certain limitations. First, most participants were women in their 30s diagnosed with early-stage breast cancer, and participation was limited to those who had completed active treatment and had good general health without recurrence or metastasis. Additionally, the participants were recruited from online support groups for study convenience. As the experiences of breast cancer may vary significantly based on participants' characteristics and the sociocultural context they belong to, the findings of this study cannot represent the experiences of all young women with breast cancer. Future studies should replicate this study with participants with a wider range of demographic and disease characteristics.

Second, the interviews were conducted in Korean and meticulously translated into English with the help of experts. Rigorous efforts were made to ensure accurate translation. First, a professional translator translated the Korean content into English. Then, two external qualitative researchers proficient in both Korean and English verified the study results to ensure appropriate translation. However, there remains a possibility of minor distortions in meaning stemming from the translation process.

# Clinical implication

Young women diagnosed with breast cancer face unique challenges due to the disease's pathological features and the sociocultural and developmental aspects associated with their youth. Healthcare professionals should devise multifaceted treatment and survivorship plans tailored to the needs of these young patients, focusing particularly on their physical, psychosocial, and developmental needs. Support interventions such as psychosocial counseling or peer support, can help enhance care effectiveness among young breast cancer survivors. The findings of this study have significant clinical implications for healthcare

providers. They can guide healthcare providers in providing holistic care that improves the overall well-being and quality of life of these patients.

#### **Conclusions**

This study was conducted to gain an in-depth understanding of the essential meaning of breast cancer disease in young women. This study revealed that young women with breast cancer experience unique challenges due to the physical, psychological, and developmental properties associated with their young age, along with the life-threatening disease itself. These findings provide valuable information for developing tailored interventions, ultimately contributing to improving the psychosocial adjustment and quality of life of young women diagnosed with breast cancer.

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#### CRediT author statement

Jeonghee Ahn: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing – Original draft, Writing – Review & Editing, Supervision, Funding acquisition, Project administration. Kyoung-eun Lee: Methodology, Investigation, Data curation, Formal analysis, Writing – Review & Editing. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the decision to submit for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

# **Declaration of competing interest**

The authors declare no conflict of interest.

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# **Ethics statement**

This study was approved by the Institutional Review Board (IRB No. 1040968-A-2023-003) of the researcher's institution. Before starting the interviews, the research purpose, methods, and the possibility of withdrawal from the study were thoroughly explained to the participants, and written informed consent was obtained. The interviews were recorded with participants' consent, and any personal and identifiable information of the participants was encoded when transcribing to ensure anonymity. After completing the interviews, the participants received a small reward.

# Data availability statement

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

# Declaration of Generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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