Contents lists available at ScienceDirect

# Asia-Pacific Journal of Oncology Nursing

journal homepage: www.apjon.org

Original Article

# A qualitative analysis of sexual transformation in Japanese women after ovarian cancer treatment

# Rie Matsui<sup>\*</sup>, Sanae Aoki, Natsuko Seto

Graduate School of Nursing, Kansai Medical University, Hirakata, Osaka, Japan

ARTICLE INFO	A B S T R A C T
<i>Keywords:</i> Cancer treatment Sexuality Japanese Ovarian cancer Qualitative research	Objective: Ovarian cancer treatment, involving surgery and chemotherapy, profoundly affects the psychosocial dimensions of patients, particularly their sexuality. However, detailed experiences among Japanese women with ovarian cancer have not been clarified. This study was aimed to assess the nuanced transformation of sexuality in Japanese women after ovarian cancer treatment.   Methods: Eighteen women who underwent ovarian cancer treatment were interviewed. Data were analyzed using a modified grounded theory approach by categorizing identified concepts based on nuanced relationships and meanings. The interplay among these categories was depicted as a narrative.   Results: The analysis revealed five categories and 13 subcategories that encapsulated the transformation of sexuality in ovaries and uterus; (2) contemplating the reversibility and irreversibility of womanhood; (3) grappling with altered and often negative feelings toward sexual activity; (4) reassessing the essence of partnership; and (5) finding contentment in their identity as women. Overcoming the mental and physical alterations resulting from treatment, coupled with interactions with partners, enabled women to gradually perceive themselves and their femininity positively.   Conclusions: The transformation of sexuality in Japanese women undergoing treatment for ovarian cancer unfolds in five distinct stages. This evolution appears to be influenced by the unique characteristics of ovarian cancer diagnosis and treatment, past reproductive decisions, communication dynamics with partners, and societal norms in Japan. Further research is needed to offer comprehensive care during the properative phase.

#### Introduction

Ovarian cancer predominantly affects women between the ages of 40 and 70. In Japan alone, over 13,000 new cases are reported annually.<sup>1</sup> Furthermore, the number of patients with ovarian cancer is higher in Asia compared to Western countries.<sup>2</sup> The diagnostic process for ovarian cancer presents the following challenges. First, due to the lack of any specific symptoms, screening is not feasible, and patients are often diagnosed at advanced stages of the disease. Second, surgery is essential for diagnosis, as ovarian tissue biopsy is possible only during surgery, and the diagnosis is confirmed only by pathological examination. Therefore, patients are not clearly informed regarding the specific diagnosis or treatment plan before surgery. Upon diagnosis of ovarian cancer, extensive surgery is performed on the uterus and bilateral ovaries, followed by chemotherapy. These treatments have been shown to cause long-term physical distress due to adverse events and psychological problems such as depression.<sup>3</sup>

Cancer therapy can also detrimentally affect a woman's sexual function and greatly impact her life goals, such as plans for marriage and pregnancy, self-identity, achievement of developmental tasks, and relationship with her partner (i.e., sexuality). The experiences of women who underwent ovarian cancer treatment have been clarified by multiple survey-based reports. After ovarian cancer treatment, women experience dryness and pain in the vaginal mucosa due to a prominent decrease in estrogen secretion.<sup>4,5</sup> Additionally, women have decreased sexual desire and difficulty achieving orgasms,<sup>4,6</sup> with approximately 50% of sexually active women reporting decreased sexual desire.<sup>7,8</sup> Such sexual dysfunction alters relationships with their partners. Because of the associated pain, women avoid sexual activity and become less intimate with their partners.<sup>9,10</sup> Conversely, a survey by Gershenson et al.<sup>11</sup> revealed that young ovarian cancer survivors with a good prognosis felt stronger and more satisfied with their partners compared to an age-matched control group. These experiences influence women's femininity and identity. A qualitative survey by Tetteh<sup>12</sup> showed that

\* Corresponding author. E-mail address: matsuir@hirakata.kmu.ac.jp (R. Matsui).

https://doi.org/10.1016/j.apjon.2024.100381

Received 21 October 2023; Accepted 13 January 2024

2347-5625/© 2024 The Author(s). Published by Elsevier Inc. on behalf of Asian Oncology Nursing Society. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).







approximately 40% of 28 participants experienced changes in body image after ovarian cancer treatment and perceived these changes as irreversible. Additionally, because of the loss of the uterus and ovaries, which are the symbols of femininity, the women expressed feelings of being "not perfect as women" and "having no gender," and the results showed that the women lost confidence.<sup>10,13</sup>

Gene therapy is expected to extend the lives of ovarian cancer patients; therefore, addressing issues related to patients' sexuality is crucial to enhance their overall quality of life. Sexuality is highly individualistic, and care should be taken to emphasize women's subjective experiences. As previously stated, previous studies have clarified that the sexuality of women who underwent treatment for ovarian cancer changed completely compared to that when they were healthy. However, these surveys were conducted mainly in Western countries, and there is a paucity of similar research on Japanese women. We postulated that in Japan, where the culture is relatively reserved regarding sexual matters, observations on women's sexuality may differ from those in previous research. Therefore, this study aimed to clarify changes in the sexuality of Japanese women who underwent treatment for ovarian cancer.

#### Methods

#### Definition of terms and theoretical framework

In this study, the following definition of sexuality given by Woods,<sup>14</sup> which emphasized a holistic view, was adopted: "Sexuality encompasses three dimensions—sexual functioning, sexual self-concept, and intimacy—and is an aspect of an individual's quality of life."

Furthermore, this study is based on Erikson's<sup>15</sup> "threefold realities," which were proposed as a theoretical framework: (1) the world of mere superficial facts (factuality); (2) recognizing the essence of facts as having a certain meaning (reality); and (3) actively and interactively existing in relation to others (actuality). Human beings live in reality, and these three aspects complement each other. We believe that the use of this framework will enable us to better capture women's subjective experiences of sexuality.

#### Study design

This study utilized a modified version of the grounded theory approach.<sup>16</sup> This method incorporates the principles of theoretical sampling and continuous comparative analysis of the grounded theory approach,<sup>17</sup> while emphasizing the context of the participants' narratives, ensuring data integrity, and capturing the dynamism of phenomena. This design concept was adopted because sexuality is a holistic concept, and we aimed to determine the dynamic phenomenon of the transformation of sexuality.

#### Participants

The eligibility criteria were as follows: (1) Japanese women aged 20–55 years; (2) those who had a history of ovarian cancer and had undergone initial treatment for ovarian cancer; (3) those who had participated in a patient association; and (4) those who were mentally stable and able to talk about personal experiences. Women diagnosed with any other type of cancer (metastasis of ovarian cancer was not considered in this category) were excluded. Participants were recruited by representatives of three patient associations in Japan, who invited women who met the criteria to participate in the study. Additionally, recruitment articles were posted on patient association websites and social media. Those willing to participate were contacted directly by the researchers via email. Participants were recruited between November 2020 and June 2021.

#### Data collection

As a general rule, two face-to-face or online interviews were conducted for each participant. In the first interview, an interview guide, created based on a theoretical framework, was used to ask participants about changes in their sexuality owing to the diagnosis and treatment of ovarian cancer. Sample questions included the following: "How did you perceive changes in your sexual function?" "Has there been a change in your identity as a woman?" "How do you communicate affection with your partner?" and "What do you think the experience meant to you?" In the second interview, the participants were asked to confirm whether the researchers had properly interpreted the content of the first interview, and further explanations were requested regarding the key points. Each interview was recorded with the participants' permission.

#### Data analysis

Data were analyzed using a modified grounded theory approach<sup>18</sup> as follows:

- (i). The recorded content of each interview was transcribed verbatim. The focus of the analysis was on "women who have undergone ovarian cancer treatment," with the central analysis theme being "the transformation of sexuality after ovarian cancer diagnosis and initial treatment." The verbatim transcripts were reviewed multiple times to ensure accuracy.
- (ii). A worksheet consisting of "concept name," "definition," "variation," and "theoretical memo" was used for the analysis. One sheet was created for each concept. After interviewing three participants, we selected one case that gave the richest narrative and wrote down the important context in the "variation" worksheet in light of the analysis theme. We interpreted the meaning of this variation, described it as a "definition," and gave it a "concept name" that expressed the definition concisely. In this process, the researcher's thought interpretations and ideas were written down as a "theoretical memo."
- (iii). After analyzing the first case, the above procedure was repeated for the second case onward. When adding variations to previously generated concepts, we compared and examined them from similar and opposite perspectives. We then checked the consistency of the definitions and concept names and modified the definitions and concept names as necessary. When a concept was generated but lacked specific examples, it was either integrated with other concepts or deleted. Steps (ii) through (iii) were performed independently by the authors and then discussed among the researchers until an agreement was reached.
- (iv). After analyzing the data for 12 cases, we evaluated the completeness of the concepts based on the abundance of specific examples for each concept. As a result, we determined that additional data collection were required. No new concepts were generated after the 15th case, and the data of three additional cases were added; however, the situation remained the same. It was determined from this that the theoretical saturation was reached.
- (v). The concepts created were categorized by examining the similarities and differences in meaning and relationships between concepts. The relationships among these categories were visualized and described as a story.

#### Ensuring reliability

Data analysis were iteratively refined until interpretations among the three researchers were consistent. In the second round of interviews, participants were asked to confirm that the researchers' interpretations were correct. We also explained the results of the final analysis to the five administrators of the patient association and asked them for their opinions on whether the phenomena were represented appropriately. After the three researchers reviewed the data and worksheets, corrections were made to aspects indicated by them, such as the appropriateness of the concept names, until a consensus was reached among all.

#### Ethical considerations

This study was approved by the Ethics Review Committee of Kansai Medical University (approved on August 7, 2020, IRB No. 2020059). The participants were given written explanations of the study purpose and methods, freedom to participate in and withdraw from the study, assurance of anonymity, method of data management, and publication of results. Written informed consent to participate in the study was obtained from all participants. Participants were assured that they could stop the interview if they experienced distress or discomfort. The researcher carefully observed participants' reactions during the interview to assess their ability to continue. This study was conducted in accordance with the tenets of the Declaration of Helsinki.

#### Results

The study initially recruited 20 participants; however, one withdrew due to the resumption of treatment, and another withdrew citing a lack of confidence to discuss the topic. As a result, 18 people ultimately participated in the study. The average age of the participants was 44.6 years (range 29–52 years), and the average number of years since diagnosis was 5.1 years (0.5–18.7 years). All 18 participants underwent surgical therapy, and 15 underwent chemotherapy. Sixteen participants were in remission, and two had progressive disease at the time of the study. This study included five people who underwent fertility treatment. The participants' characteristics are presented in Table 1. The total duration of interviews varied from 71 to 200 min per person, with an average duration of approximately 101 min.

A total of five categories and 13 subcategories elucidating the women's experiences were generated from the analysis (Table 2), and the relationships among the categories were schematized (Fig. 1). The story line or the narration of their experiences is described below using **categories** and "*subcategories*." Note that the letters in the story line text are the same as those in Fig. 1.

#### Story line

In the first stage, when the possibility of having ovarian cancer was indicated to them, women had an experience where they confronting the reality of losing their ovaries and uterus. Initially, women noticed unusual symptoms, but they dismissed them as symptoms of aging and not as a serious illness. However, physicians informed them regarding the possibility of ovarian cancer and the necessity of surgery for a definitive diagnosis. At that time, the women felt that they had no choice but to lose their ovaries and uterus; however, they were reluctant to part with what defined their femininity. They then underwent surgery while "*unable to give up hope for the preservation of their reproductive organs*." Women felt that their reproductive organs had been "taken" when they woke up from the anesthesia. These women then found it difficult to face their bodies and became "*bewildered by sudden changes in their minds and bodies*."

When chemotherapy was started after surgery, the women tried to "*reassuring themselves that the adverse events are temporary*" to dispel feelings of self-pity owing to hair loss, weight changes, and so forth. However, they also had a "*recognition of the inevitable reality*," wherein they recognized that they would never be able to have children again and regretted past fertility treatments and relationships with men, which they believed were related to their ovarian cancer. Specifically, this experience involved contemplating the reversibility and irreversibility of womanhood, and women sought answers to this question.

No. (	Condition ¿	Condition at diagnosis			Uvarian cancer	ian cancer diagnosis and treatment			
. 1	Age Ma	Marital status	Presence of children	Fertility treatment	Disease stage	Time since diagnosis (year)	Operation	Adjuvant therapy	Hormone replacement
1	40s Ma	Married	Yes	Yes	Ш	6.9	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	Yes
5	40s Ma	Married	No	Yes	П	1.8	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	Yes
ہ ۳	40s Ma	Married	Yes	No	III	5	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	Yes
4	40s Ma	Married	Yes	No	N	5	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	No
10	40s Sin	Single	No	No	I	1.5	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	Yes
	50s Ma	Married	No	No	I	0.9	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	No
7	40s Ma	Married	Yes	No	I	5.1	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	Yes
~	40s Ma	Married	No	Yes	П	2.6	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	No
•	40s Ma	Married	Yes	Yes	I	0.5	Bilateral oophorectomy/hysterectomy	No	No
01	30s Ma	Married	Yes	No	I	0.8	Bilateral oophorectomy/hysterectomy, lymphadenectomy	No	Yes
.1	40s Ma	Married	Yes	No	III	8.9	Bilateral oophorectomy/hysterectomy	Yes	No
[2	50s Sin	Single	No	No	I	8.8	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	No
2 2	30s Sin	Single	No	No	I	18.7	Unilateral oophorectomy	Yes	No
4	50s Ma	Married	Yes	No	П	12.3	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	No
15	50s Sin	Single	No	No	III	8.7	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	No
16 5	50s Ma	Married	Yes	No	III	1.1	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	No
17 4	40s Ma	Married	Yes	Yes	III	2	Bilateral oophorectomy/hysterectomy, lymphadenectomy	Yes	No
18 2	20s Sin	Single	No	No	I	1.3	Unilateral oophorectomy	No	No

Overview of study participants

Catagorias and subcatagorias

Table 2

Category $(n = 5)$	Subcategory ( $n = 13$ )	Participants who provided data (Participants No.)
Confronting the reality of losing	Unable to give up hope for the preservation of their reproductive organs	1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13, 17, 18
their ovaries and uterus	Bewildered by sudden changes in their minds and bodies	1, 5, 7, 8, 9, 10, 11
Contemplating the reversibility	Reassuring themselves that the adverse events are temporary	1, , 2, 3, 4, 5, 6, 7, 8, 14, 17
and irreversibility of womanhood	Recognition of the inevitable reality	1, 2, 3, 5, 7, 8, 9, 10, 13, 14, 18
Grappling with altered and	Self-assessment of their perceived inadequacies as a partner	3, 4, 8, 9, 14
often negative feelings toward	Trying to find meaning in responding to their partner's sexual desire	1, 2, 5, 8, 9, 11, 12
sexual activity	Suffering related to sexuality that others cannot understand	3, 5, 8, 9, 10, 11, 12, 15
Reassessing the essence of	Receiving love from their partners	1, 3, 4, 8, 9, 10, 11, 14, 16, 17
partnership	Discovering new ways of expressing affection	2, 3, 4, 6, 8, 10
	Bonds with partners are broken	2, 5, 8, 11, 12, 15, 18
	Reconsideration of their partnerships while considering the implications of ovarian cancer	1, 2, 3, 4, 5, 7, 8, 11, 12, 13, 17, 18
Finding contentment in their	Perception that their female function was restored	5, 7, 13, 14, 18
identity as women	Fully accept themselves identity as women	3, 4, 6, 7, 8, 11, 13, 15, 16, 18

Toward the end of the treatment, women began grappling with altered and often negative feelings toward sexual activity. The fear of scarring from surgery or feeling unwell prevented them from resuming their sexual activities, and they engaged in a "self-assessment of their perceived inadequacies as a partner." Women who resumed sexual activity experienced a feeling of emptiness and pain during sexual activity; they derived no pleasure from it; therefore, they "trying to find meaning in responding to their partner's sexual desire." They suffered from forced menopause and expressed their troubles with sexual activities as a "suffering related to sexuality that others cannot understand," and this further reinforced their "self-assessment of their perceived inadequacies as a partner" and "trying to find meaning in responding to their partner's sexual desire."

Moreover, women began reassessing the essence of partnership. The women "receiving love from their partners" through casual everyday behavior. As a result, love for their partner deepened, and the couple "discovering new ways of expressing affection." However, in some instances, the inability to share their minds and bodies as a couple led to "bonds with partners are broken." Based on these changes in the couples' relationships, women experienced "reconsideration of their partnerships while considering the implications of ovarian cancer."

Through this process, they gradually came to "*fully accept themselves as women*," irrespective of the societal expectations of femininity in Japan. Among them, women who had one ovary preserved and those who received estrogen therapy gained significant confidence with the "*perception that their female function was restored*." Thus, women undergoing treatment for ovarian cancer viewed themselves in a positive light and were finding contentment in their identity as women owing to fluctuations in their sexuality.

#### The five categories

#### Confronting the reality of losing their ovaries and uterus

In this category, even if the women were told before surgery that their ovaries and uterus would need to be removed if they were diagnosed with ovarian cancer, they could not shake off the feeling of denial. It was

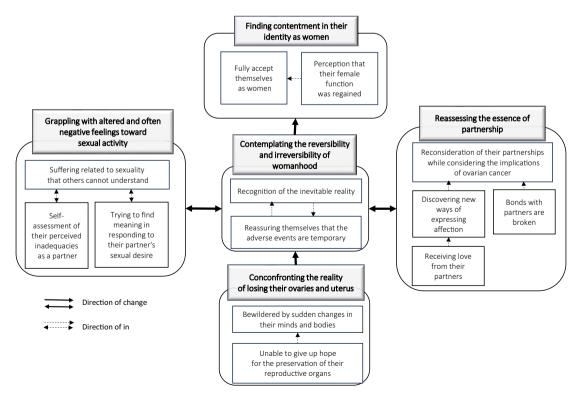


Fig. 1. An illustration depicting the relations between categories and subcategories.

only after the surgery that what had happened to their bodies became a reality. This was experienced in the early stages of initial treatment, from preoperative to postoperative recovery.

"Unable to give up hope for the preservation of their reproductive organs". Women tended to think that their ovaries and uterus had a meaning other than merely providing them with the ability to give birth, and they hesitated to have to remove them. One participant stated the following:

I told the doctor to preserve the uterus if possible if the tumor was benign. The physician asked why, and I said that my body has it because it needs it. It might not be a problem even if it were taken away, but I think that it is in my body precisely because it is necessary. Moreover, I never had any problems with my uterus, so I don't think it is necessary to remove it (No. 9).

"Bewildered by sudden changes in their minds and bodies". Women found it difficult to accept the changes in their minds and bodies after surgery. Several participants expressed that they felt as if their ovaries and wombs had been exploited.

It started with suspected cancer, and then I got on the operating table and lost consciousness. I woke up, and then I was told by the doctor that it was cancer ... My uterus and ovaries had already all been removed ... I just had to accept it, and it just happened without me having any time to think ... I couldn't organize my feelings (No. 1).

#### Contemplating the reversibility and irreversibility of womanhood

In this category, women perceived that their own appearance and self-perception were altered by surgery or chemotherapy. They questioned whether they would be able to return to the state they were in when they were healthy after treatment.

"Reassured themselves that the adverse events are temporary". The women consoled themselves that changes due to postoperative complications or side effects of chemotherapy were temporary and that they could return to how they were before. These changes included hair loss, skin color variations, limb numbness, and edema. One participant said that she tried not to perceive changes in appearance due to hair loss as unfavorable.

For the time being, I thought that it was the only time I could do this, so I had fun arranging my wigs and taking pictures. I think I faced the adversity by having fun (No. 8).

"Recognition of the inevitable reality". Women recognized the reality that even if they overcome ovarian cancer in the future, they will have to bear the repercussions for the rest of their lives. Several participants experienced a sense of emptiness, deprived of the choice to have or not have children, regardless of their fertility status or desire for children before treatment.

Up until now, I have lived without actively wanting children. However, there is a profound distinction between being able to have children and not being able to have children. There is no change in the current circumstances, but no matter what I say, I wonder if my words will be dismissed as sour grapes. ... I felt a sense of loss for the first time at that point (No. 5).

Additionally, women who underwent fertility treatment blamed themselves for linking the affliction of ovarian cancer to fertility treatment.

I wonder if I overdid the fertility treatment. I should have stopped before my body protested. In some sense, there is a part of me that feels apologetic toward myself (No. 2).

Grappling with altered and often negative feelings toward sexual activity

In this category, women develop negative feelings toward sexual activity because their bodies and minds do not react to sexual activity as before.

"Self-assessment of their perceived inadequacies as a partner". Avoiding sexual activity because of physical and mental pain results in women assessing themselves as inadequate in fulfilling their roles as partners. One participant stated the following:

My partner is still in his 40s, but he can no longer engage in sexual activity, and I feel sorry for him and a great sense of responsibility. I think that I should do something, but even that has become tiring (No. 4).

"Trying to find meaning in responding to their partner's sexual desire". While experiencing pain during sexual activities, women tell themselves that this is their role and obligation, and they respond to their partners' demands. Several women who resumed sexual activity after treatment were unable to enjoy it with their partners because of decreased sexual desire, pain during sexual intercourse, a lack of sexual pleasure, and a fear of rupture of surgical wounds.

It really has just become a painful time ... I feel like I've become a sex doll ... I often get turned off during sex, and I think, What am I doing? ... But I do think that this is my role as a wife (No. 2).

"Suffering related to sexuality that others cannot understand". Women experienced sexual dysfunction that a third party could not understand. Many participants were unable to talk to anyone about their sexual concerns. Additionally, women believed that medical professionals did not take these concerns seriously because ovarian cancer is a serious disease. One participant expressed resentment, particularly regarding menopausal symptoms.

If I were still young, I might not have felt this way. What is really frustrating is that I lost all my ovaries and went through forced menopause. All the menopausal symptoms at once, like falling over a cliff... all the symptoms that were supposed to appear gradually appeared, but ... I could feel the doctor's contempt, knowing that the situation would be the same in a few years even if I didn't remove the ovaries anyway ... I might be paranoid, but I felt like I was treated rudely regarding my concerns about menopause (No. 5).

#### Reassessing the essence of partnership

In this category, women reevaluated their relationships with their partners and determined whether they could continue to spend their lives together.

*"Receiving love from their partners".* This means that women felt loved through their partners' words and actions. These words and actions were not direct expressions of affection; instead, the women interpreted shifts in their partner's daily behavior as signs of affection towards them. This also deepened their affection for their partners.

I'm not really good at it; neither of us can say I love you in words directly. So, for example, I would try to express family ties by saying things like, 'My son and dad are both important family members.'... It's the same with my husband. My husband would say to our son, such that I could hear him, 'Mom is sick, so the two of us men should support and protect her' (No. 17).

*"Discovering new ways of expressing affection".* Men and women found new ways of expressing affection that were mutually satisfying. This required a mutual understanding of the altered mental and physical conditions owing to the ovarian cancer treatment.

I think that a marital relationship can be established even without sex. Sometimes, I feel like hugging, so I started to express affection in this way. Past physical expressions of affection were sexual activities and kisses, but... if you ask me if it's fine like this, I would answer that's not the case, and I'd like to try again, but there's no opportunity for that (No. 3).

*"Bonds with partners are broken".* There was a gradual distortion in women's relationships with their partners. In particular, this was due to the fact that differences in sexual needs could not be filled. The following was the experience of an unmarried woman in a relationship.

I gradually hated having sex, and we eventually broke up. He was still young, so he wanted something different from me. I thought that it would be impossible to continue the relationship like this. But he didn't think so. The only feelings I had regarding sex were hate, and it kept coming up. So, I gradually couldn't see him anymore (No. 12).

"Reconsideration of their partnerships while considering the implications of ovarian cancer". Women began reevaluating their relationships with their partners while anticipating the course of their disease. One participant believed that her partner would be her lifelong partner, regardless of how her ovarian cancer progressed.

We are no longer having sex, but I appreciate that he is kind of there for me. So, now I can't even work, and my husband takes care of everything, but he makes me feel that I can be here ... because he's there (No. 11).

Meanwhile, women who broke up with their partners went through a trial-and-error process regarding their dealings with the opposite sex in the future.

In the case of dating for the purpose of having a child, although one's own fertility and the partner's reproductive function are prerequisites, I don't want to consider just one criterion when choosing a partner. I want to prioritize living with that person and living together (No. 13).

#### Finding contentment in their identity as women

In this category, despite acknowledging the aspects of their femininity that had changed owing to ovarian cancer treatment, the women learned to discover what remained unaltered or what they wanted to cherish and accepted their current selves.

"Perception that their female function was restored". Women perceived that their sexual function had been restored and was similar to that before ovarian cancer treatment. This includes women in whom menstruation was resumed owing to sparing of the ovaries during treatment, women who successfully underwent ovarian hormone replacement therapy, and those who could experience sexual pleasure.

When my menstruation resumed, I thought to myself, 'Oh, it's back to normal.' I felt a strange sense of accomplishment, as if the bad parts were completely gone, leaving the essential parts intact. I remember that feeling very well. That it had finally come back. I think it was about a year after the treatment ended. That my body had recovered (No. 13).

"Fully accept themselves as women". Although the degree of acceptance varied, all participants experienced a sense of satisfaction in accepting and embracing who they are now. Many participants noticed that their ways of life as woman or what they cherished did not change, even after undergoing ovarian cancer treatment. They also drew a self-image as women who were not affected by the societal norms of femininity.

Before I was sick, I was not pursuing femininity. I think that was probably an inferiority complex. I really wanted to reject femininity and dismiss it. I wanted to reject the notion that women should not be assertive. But that's not because they are women. I felt that if I can't do it, I should live life the way I want (No. 3).

#### Discussion

This study describes the factors that influence the transformation of sexuality of Japanese women who underwent treatment for ovarian cancer.

#### Diagnosis and treatment features of ovarian cancer

In the preoperative and early postoperative phases, confronting the reality of losing their ovaries and uterus. The preoperative women underwent surgery while *"unable to give up hope for the preservation of their reproductive organs."* After surgery, they experienced a feeling that their uterus and ovaries were suddenly taken away, although physicians had informed them of the possibility of extensive surgery, including the removal of reproductive organs, if they were diagnosed with ovarian cancer, and they had provided consent. Nevertheless, it appears that this seemed like a sudden event to them. This was because a confirmation of ovarian cancer diagnosis could not be provided before the operation; therefore, the operation was conducted with women having some hope that they may be able to preserve their ovaries.

Additionally, ovarian cancer patients at the diagnosis stage try to maintain hope and actively participate in the decision-making process for their treatment to achieve psychological stability, even under the extreme stress stemming from their awareness of the possibility of death.<sup>18-20</sup> Other patients ignore subjective symptoms or try to avoid reality by considering the best outcome.<sup>21,22</sup> However, as in the present study, the complex psychology in which the expectation of preservation of reproductive organs, regardless of fertility, cannot be abandoned has not been clarified. When women are faced with the possibility of losing their reproductive organs, it forces them to think about the possible implications, and they experience a feeling of attachment to their ovaries and uterus. Additionally, for ovarian cancer, if advanced disease is predicted, surgery should be performed as soon as possible, and chemotherapy should be started immediately after surgery. The postoperative experience of being "bewildered by sudden changes in their minds and bodies" is owing to the fact that the women have no choice but to proceed with treatment; they feel akin to that, as if they are being swept away without being able to grasp what is happening to themselves. Specifically, they are informed that their lives are in danger and that they are not given room or enough time to make any decisions,<sup>23</sup> which causes this experience. This experience, described as a loss of autonomy by Jelicic et al.,<sup>18</sup> may be common among ovarian cancer patients during the diagnostic phase.

#### Past reproductive decisions

In the aspect of contemplating the reversibility and irreversibility of womanhood, the women were affected by their reproductive choices before they were diagnosed with ovarian cancer. Five study participants had experience with fertility treatment but regretted their choice after being diagnosed with ovarian cancer. This may be due to the perception that long-term ovarian hormone replacement therapy is a causative factor for ovarian cancer. In a study by Pozzar et al.,<sup>22</sup> fertile women were informed of the risk of fertility loss before surgery and took actions such as deciding to preserve the ovary or initiating the adoption process. These actions are important for preserving self-image. However, many of the participants in this study were in their 30s and 40s, a time when adequate fertility was not expected and the option of fertility preservation was not recommended. In addition, many women of this generation in Japan prioritize their careers over having children. This may reflect the fact that Japan's gender gap index ranks 116th out of 146 countries,<sup>24</sup> which is extremely low among developed countries. When the women in the study

lost their fertility completely because of ovarian cancer treatment, they experienced irreversible regret regarding their past choices and lifestyles. As a result, their identity as women was severely affected.

#### Communication patterns with partner

For the aspects of grappling with altered and often negative feelings toward sexual activity and reassessing the essence of partnership, closed communication due to the female-specific nature of the disease had an impact. Women were unable to verbally convey to their partners their feelings of inability to engage in sexual intercourse or the changes in their bodies owing to treatment in the same way as they did when they were healthy. Takahashi et al.<sup>25</sup> investigated the relationship between communication patterns and the mental health of Japanese women with cancer and their spouses. The results clarified that self-disclosure from the partner was related to depression and anxiety in both partners, and the more the patient became aware of the loss of femininity, the more unproductive the couple's communication tended to be. This shows the importance of sharing thoughts and feelings between couples as well as the difficulty of conveying the experience of loss of femininity, which is unique to women, to their partners.

Spouses of patients with cancer strive to connect with their patients amid anxiety and conflict in their daily lives.<sup>26</sup> However, a survey of spouses of patients with gynecologic cancer<sup>27</sup> found that male partners continued to feel the burden of not fully understanding the psychology of women with this disease. These findings illustrate the existing dynamics among couples, where understanding each other, despite the desire to do so, proves challenging. In addition, a study<sup>28</sup> with early-stage breast cancer patients and their partners has shown that protective buffering, aimed at shielding partners from cancer-related concerns, can lead to reduced intimacy and increased fear of recurrence. Thus, challenges with self-disclosure by women with ovarian cancer and their partners may be attributed to the impact of protective buffering on changes in intimacy.

In the present study, there were multiple cases of relationship breakdown among unmarried couples. Furthermore, sexual intercourse is an important means of communication for unmarried couples to sustain their relationships. Finding alternatives to sexual intercourse is difficult for women after ovarian cancer treatment because of the time and effort involved.

#### Social conventions in Japan

All the aforementioned aspects of sexuality are influenced by Japanese societal norms. During Japan's historical transition, women's sexuality and reproduction have been greatly suppressed under the law. In particular, patriarchy has not yet been eliminated.<sup>29</sup> Our results are based on such customs that are firmly rooted in Japan. Ehara<sup>30</sup> stated that gender roles are unconsciously habituated and associated with body perceptions and emotions. The participants also struggled with the gap between themselves and the idealized image of a desirable Japanese woman who would give birth, raise a child, and devote herself to her husband. Ultimately, many women experienced an increase in self-esteem after they freed themselves from these social conventions and freely redefined their femininity. A survey of middle-aged Japanese women with genital and breast cancers<sup>31</sup> showed that patients had broadened their horizons regarding ways of living as women and became aware of the need to love themselves while embracing their new identities as women who cannot bear children and break away from gender roles; these findings were similar to those reported in this study. These were found to be common experiences among middle-aged Japanese patients affected by cancers that are specific to women. It is thought that women who play a central role in society during this period will be able to portray themselves by responding to the role expectations of those around them, even after cancer treatment.

#### Application to nursing practice

The first application is support for treatment decision-making and preparation. Preoperatively, the patient's prior history, her perception of her own medical condition, and the extent of her knowledge about ovarian cancer are recorded. Consequently, in preoperative interviews, it is necessary to explain to all women, as a general rule, how their sexuality can change and to provide information according to their needs, regardless of age or fertility. In the future, it is also important to assess whether changes in sexuality have a significant impact on women based on the presence or absence of a partner, the frequency of sexual intercourse, and patterns of communication.

Next, when it is time to resume their lives with their partners, it is necessary to help women properly understand the symptoms caused by the treatment and explain to their partners the causes, factors that reduce or enhance them, and their sexual desires. It is extremely important to seek advice on relationships with partners and sexual intercourse during this period, and opportunities should be created intentionally.

During the period when women are likely to have negative feelings owing to mental and physical changes after treatment, it is necessary to encourage them to express their thoughts and feelings and to accept themselves the way they are. This involvement is believed to promote awareness among women. It was also suggested that women's ability to fulfill their social roles is one of the factors that increases their selfesteem. Therefore, it is important to support employment and household role performance, where possible, depending on the symptoms and adverse events of ovarian cancer.

Ovarian cancer is highly likely to recur even after remission with the initial treatment. Therefore, women receive medical care in a variety of setups according to their situation, such as an outpatient clinic, ward, or outpatient chemotherapy room. Therefore, it is necessary to establish a cooperative system among nurses in outpatient departments, wards, and outpatient chemotherapy units with the aim of providing seamless care. Furthermore, it is necessary to improve the practical abilities of general nurses to provide sexuality-related care.

## Limitations and future scope of this study

First, the small number of participants included in this study and the qualitative nature of this research limit the generalizability of the results. Additionally, the participants in this study were younger than the average age of those affected by ovarian cancer. To varying degrees, the positive changes experienced by all participants may be attributed to their understanding of their own cancer experience through the interviews. The impact of their interactions with the researchers cannot be completely ruled out. Further quantitative studies on women with ovarian cancer and their partners are required. We may then be able to refine this model and develop an ongoing preoperative sexual care program.

## Conclusions

The sexuality of women who have undergone ovarian cancer treatment begins with the situation where they confronting the reality of losing their ovaries and uterus. After contemplating the reversibility and irreversibility of womanhood, grappling with altered and often negative feelings toward sexual activity, and reassessing the essence of partnership, the women undergo a transformation in which they finding contentment in their identity as women. This transformation is thought to be influenced by the characteristics of ovarian cancer diagnosis and treatment, past reproductive decisions, communication patterns with partners, and social conventions in Japan.

## Ethics statement

This study was approved by the Ethics Review Committee of Kansai Medical University (IRB No. 2020059). Written informed consent to participate in the study was obtained from all participants.

#### Funding

This work was supported by the JSPS KAKENHI (Grant No. 19K10920). The funder had no role in the study design; in the collection, analysis or interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

#### CRediT authorship contribution statement

**Rie Matsui**: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Funding acquisition, Visualization, Project administration, Writing – Original Draft, Writing – Review & Editing. **Sanae Aoki and Natsuko Seto**: Formal analysis, Supervision, 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.

#### Data availability statement

The data that support the findings of this study are available on request from the corresponding author, Rie Matsui. The data are not publicly available due to ethical restrictions.

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

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

#### References

- Cancer Statistics in Japan. Cancer Information Service, National Cancer Center, Japan (National Cancer Registry, Ministry of Health, Labour and Welfare). https ://ganjoho.jp/reg\_stat/statistics/data/dl/index.html. Accessed 30 September 2023.
- World Ovarian Cancer Coalition, Atlas. In: Global trends in incidence, mortality, and survival; 2020. https://worldovariancancercoalition.org/wp-content/uploads/2020/ 10/2020-World-Ovarian-Cancer-Atlas\_FINAL.pdf. Accessed 30 September 2023.
- Reid F, Bhatla N, Oza AM, et al. The World Ovarian Cancer Coalition Every Woman Study: identifying challenges and opportunities to improve survival and quality of life. *Int J Gynecol Cancer*. 2021;31(2):238–244. https://doi.org/10.1136/ijgc-2019-000983.
- Fischer OJ, Marguerie M, Brotto LA. Sexual function, quality of life, and experiences of women with ovarian cancer: a mixed-methods study. *Sex Med.* 2019;7(4): 530–539. https://doi.org/10.1016/j.esxm.2019.07.005.
- Dandamrongrak P, Chaiwong S, Ekalaktam P, Achariyapota V. Sexual dysfunction in Thai gynecologic malignancies survivors: a single-institutional cross-sectional observational survey. J Obstet Gynaecol Res. 2021;47(11):4005–4013. https:// doi.org/10.1111/jog.14980.
- Guntupalli SR, Sheeder J, Ioffe Y, et al. Sexual and marital dysfunction in women with gynecologic cancer. Int J Gynecol Cancer. 2017;27(3):603–607. https://doi.org/ 10.1097/IGC.000000000000906.
- Hopkins TG, Stavraka C, Gabra H, Fallowfield L, Hood C, Blagden S. Sexual activity and functioning in ovarian cancer survivors: an internet-based evaluation. *Climacteric.* 2015;18(1):94–98. https://doi.org/10.3109/13697137.2014.929104.

- Hubbs JL, Dickson Michelson EL, Vogel RI, Rivard CL, Teoh DGK, Geller MA. Sexual quality of life after the treatment of gynecological cancer: what women want. *Support Care Cancer*. 2019;27(12):4649–4654. https://doi.org/10.1007/s00520-019-04756-7.
- Wilmoth MC, Hatmaker-Flanigan E, LaLoggia V, Nixon T. Ovarian cancer survivors: qualitative analysis of the symptom of sexuality. Oncol Nurs Forum. 2011;38(6): 699–708. https://doi.org/10.1188/11.ONF.699-708.
- Boding SA, Russell H, Knoetze R, Wilson V, Stafford L. 'Sometimes I can't look in the mirror': recognising the importance of the sociocultural context in patient experiences of sexuality, relationships and body image after ovarian cancer. *Eur J Cancer Care*. 2022;31(6):e13645. https://doi.org/10.1111/ecc.13645.
- Gershenson DM, Miller AM, Champion VL, et al. Reproductive and sexual function after platinum-based chemotherapy in long-term ovarian germ cell tumor survivors: a Gynecologic Oncology Group Study. J Clin Oncol. 2007;25(19):2792–2797. https:// doi.org/10.1200/JCO.2006.08.4590.
- Tetteh DA. "I Feel Different": ovarian cancer and sexual self-concept. Womens Reprod Health. 2017;4(1):61–73. https://doi.org/10.1080/23293691.2017.1276371.
- Wittmann D, Mehta A, Northouse L, et al. True NTH sexual recovery study protocol: a multi-institutional collaborative approach to developing and testing a web-based intervention for couples coping with the side-effects of prostate cancer treatment in a randomized controlled trial. *BMC Cancer*. 2017;17(1):664. https://doi.org/10.1186/ s12885-017-3652-3.
- Woods NF. Toward a holistic perspective of human sexuality: alterations in sexual health and nursing diagnoses. *Holist Nurs Pract.* 1987;1(4):1–11. https://doi.org/ 10.1097/00004650-198708000-00004.
- Erikson E, Erikson J. The life cycle completed. In: Extended Version with New Chapters on the Ninth Stage of Development. New York: W.W. Norton & Company; 1998:89–92.
- Kinoshita Y. Practice of Grounded Theory Approach: Invitation to Qualitative Research. Tokyo: Kobundo; 2003:42–46.
- Glaser B, Strauss A. Discovery of Grounded Theory: Strategies for Qualitative Research. 1st ed. Routledge; 1999. https://doi.org/10.4324/9780203793206.
- Jelicic L, Brooker J, Shand L, et al. Experiences and health care preferences of women with ovarian cancer during the diagnosis phase. *Psycho Oncol.* 2019;28(2):379–385. https://doi.org/10.1002/pon.4952.
- Seibaek L, Petersen LK, Blaakaer J, Hounsgaard L. Hoping for the best, preparing for the worst: the lived experiences of women undergoing ovarian cancer surgery. *Eur J Cancer Care.* 2012;21(3):360–371. https://doi.org/10.1111/j.1365-2354.2011.01313.x.
- Simacek K, Raja P, Chiauzzi E, Eek D, Halling K. What do ovarian cancer patients expect from treatment?: perspectives from an online patient community. *Cancer Nurs.* 2017;40(5):E17–E27. https://doi.org/10.1097/NCC. 000000000000415.
- Boban S, Downs J, Codde J, Cohen PA, Bulsara C. Women diagnosed with ovarian cancer: patient and carer experiences and perspectives. *Patient Relat Outcome Meas*. 2021;12:33–43. https://doi.org/10.2147/PROM.S272688.
- Pozzar RA, Berry DL. Preserving oneself in the face of uncertainty: a grounded theory study of women with ovarian cancer. Oncol Nurs Forum. 2019;46(5):595–603. https://doi.org/10.1188/19.Onf.595-603.
- Tsai LY, Tsai JM, Tsay SL. Life experiences and disease trajectories in women coexisting with ovarian cancer. *Taiwan J Obstet Gynecol.* 2020;59(1):115–119. https://doi.org/10.1016/j.tjog.2019.11.032.
- World Economic Forum. The Global Gender Gap Report; 2022. https://www3.wefor um.org/docs/WEF\_GGGR\_2022.pdf. Accessed October 3, 2023.
- 25. Takahashi K, Iwabuchi M. The study of the communication between female cancer patients and their partner effect on their mental health. *Annu Rep Graduate School Educ Tohoku Univ.* 2014;63(1):141–157.
- Takahashi K. A clinical psychological study on communication about conflicts between patients with advanced cancer and their spouses. J Contemp Behav Sci. 2020; 36:12–21. https://doi.org/10.15113/00015089.
- Matsui R, Kataoka J, Nunotani M. Spouses of patients with gynecologic cancer who repeatedly receive chemotherapy: their coping strategies. J Jpn Soc Cancer Nurs. 2020;34:136–144.
- Perndorfer C, Soriano EC, Siegel SD, Laurenceau JP. Everyday protective buffering predicts intimacy and fear of cancer recurrence in couples coping with early-stage breast cancer. *Psycho Oncol.* 2019;28(2):317–323. https://doi.org/10.1002/ pon.4942.
- Inoue T. Feminism in Japan: 150 Years of People and Thoughtsvol. 2021. Tokyo: Yuhikaku; 2021:18–27.
- 30. Ehara Y. Self-determination and Gender. Tokyo: Iwanami Shoten. 108-117.
- Ueta I, Ota H, Ono M, et al. Exploring the psychological adjustment of female cancer survivors in terms of femininity. *Shikoku Acta Med.* 2020;76(1-2):73–82.