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ORIGINAL ARTICLE

Experience of Japanese pregnant women with cancer in decision-making regarding cancer treatment and obstetric care

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Abstract

Aim: Women who are diagnosed with cancer during pregnancy must make difficult, life-changing decisions that affect their own life and that of their fetus. The psychological impact of distress and anxiety resulting from facing often conflicting choices can greatly influence survival in these women. We conducted this study to clarify the experience of pregnant women with cancer in decision-making and to consider the role of nurses in providing care to pregnant women with cancer during their decision-making.

Methods: This qualitative study included post-partum Japanese women diagnosed with cancer who had made any treatment or pregnancy decisions. Data collection was conducted using semi-structured interviews and medical record review. Data were analyzed using qualitative content analysis and classified into subcategories, categories, themes, and phases.

Results: Participants comprised eight women with leukemia and cervical, breast, and digestive cancers. The decision-making experiences of these eight pregnant women with cancer were categorized into three phases: the interaction between the woman and her fetus, family members, and medical staff; confrontation with dilemma and uncertainty; and redefinition of the women's own decisions.

Conclusions: The experience of Japanese pregnant women with cancer in decision-making has two aspects: verbal and nonverbal communication with their surroundings and reflection. The role of a nurse is to guarantee these women continuous communication channels and frank dialogue, to empower them in expressing their thoughts and informational needs to medical staff and family members.

KEYWORDS

cancer, decision-making, Japanese, pregnant women

1 | INTRODUCTION

Cancer is diagnosed in approximately one per 1,000 pregnant women. Every 5 years, the likelihood of receiving treatment during pregnancy increases, mainly related to an increase of chemotherapeutic treatment (Cardonick, Gringlas, Hunter, & Greenspan, 2015; de Haan et al., 2018). In recent years, guidelines have been developed for the management of pregnant women with cancer including breast cancer, cervical cancer, and hematologic malignancy (Amant et al., 2014; Lishner et al., 2016; Loibl et al., 2015; Peccatori et al., 2013). However, qualitative research on

pregnant women with cancer is inadequate, and the experiences of these women in decision-making are unclear.

In Japan, artificial abortion at less than 22 weeks of pregnancy is a legal option. In addition, it is not common in Japan for people who do not give birth to their own children to become a foster parent or to adopt a child. Thus, decision-making in Japanese pregnant women with cancer can be expected to be more difficult and different from the experiences of similar women in Western countries.

An analysis of patients with cancer diagnosed during pregnancy with respect to obstetric and neonatal outcomes found that more than half of patients initiated treatment during pregnancy; the report also described a relationship between platinum-based chemotherapy and small for gestational age, and between taxane chemotherapy and neonatal intensive care unit (NICU) admission (de Haan et al., 2018). Studies on outcomes among children exposed to chemotherapy in utero have shown that many cancers can be treated, including with surgery and chemotherapy, during the second and third trimester after organogenesis in the first trimester, without significant risk to the fetus in most cases (Amant et al., 2015; Cardonick et al., 2015; Hahn et al., 2006; Pereg, Koren, & Lishner, 2008). However, the problem of limited data on the use of molecular-targeted drugs during pregnancy remains (Lambertini, Peccatori, & Azim, 2015). Two studies assessing in utero chemotherapy-exposed children reported that IQ score increased with each additional month of gestation and suggested that iatrogenic preterm delivery should be avoided whenever possible (Amant et al., 2012; Amant et al., 2015).

Among pregnant women with cancer, decision-making about cancer treatment becomes more complex compared with women with cancer who are not pregnant. Exploration of the psychosocial experiences of women diagnosed with breast cancer during or shortly after pregnancy, including a study of four women diagnosed during pregnancy, has revealed that these women must make difficult decisions that have impacts on their respective lives, the life of their fetus or infant, and those of their families. These women report high levels of anxiety and stress that are linked to conflict between concern for their babies' health, and for their own health and well-being (Ives, Musiello, & Saunders, 2012). A study of the psychological impact of cancer diagnosed during pregnancy, which included 74 women diagnosed during pregnancy, revealed that women were at higher risk of long-term distress if they had been advised to terminate their pregnancy, had had a preterm birth or cesarean delivery, and/or had undergone surgery post-pregnancy (Henry, Huang, Sproule, & Cardonick, 2012). A study of psychological distress and cognitive coping in pregnant women diagnosed with cancer and in their partners revealed that women were more inclined to want to continue the pregnancy than their partners (Vandenbroucke et al., 2017). These findings suggest that decision-making by pregnant women with cancer about cancer treatment and termination of pregnancy is psychologically quite difficult. This is because options for abortion, premature birth, and intrauterine fetal exposure have conflicting interests and differing harmful effects for the mother and fetus. In other words, it is difficult to apply existing decision support strategies. Thus, for the care of pregnant women with cancer who confront challenging decisions, there is an essential need for an individualized approach that includes adequate dialogue with a multidisciplinary team of cancer specialists, obstetricians, neonatologists, pharmacists, psychologists, social workers, and nurses (Ives et al., 2012; Moran, Yano, Al Zahir, & Farquharson, 2007; Pentheroudakis & Pavlidis, 2006; Van Calsteren & Amant, 2014; Zanetti-Dällenbach et al., 2006). However, the ways in which pregnant women require dialogue and support in decision-making are not sufficiently clear.

In this study, we explored the experiences of pregnant women with cancer in decision-making, without limiting the type of cancer at one university hospital including all types of cancer departments, obstetrics and NICU. The reason for including NICU is that the options for pregnant women with cancer are not limited. The purpose of this research was to clarify the experience of pregnant women with cancer in decision-making and to consider the role of nurses for providing care to pregnant women with cancer in their decision-making.

2 | METHODS

2.1 | Design

We adopted a qualitative design because research focusing on decision-making among pregnant women with cancer is very scarce, and the sample of this target group is a minority population. We limited our research to only one facility because the care of pregnant women with cancer who confront treatment decision-making and configurations of multidisciplinary teams differs by facility. We adopted a purposive sampling method and retrospective approach so as to include the maximum number of study participants at only one facility during a limited period. The retrospective approach might have limitations, such as recall bias; however, we chose this method to allow time for participants to make their own appraisal about decisions during pregnancy, such as feelings of satisfaction or regret.

2.2 | Strategies for achieving trustworthiness

We used qualitative content analysis (Krippendorff, 1980), which involves replicable and valid methods for making inferences from observed communications according to their

context. In this study, we retrospectively collected information about experiences of complex and conflicting decision-making in cancer treatment and obstetric care, without limiting participants' cancer types. As a result, we predicted that the decision-making context would be highly individualized and that interview responses might not be sufficiently verbalized owing to certain psychological burdens. We adopted qualitative content analysis because of its strengths of allowing for unstructured material, being noninvasive for participants, and respecting context.

We used several research strategies referred to in articles by Morse (2015) and, Graneheim and Lundman (2004) for increasing the accuracy of inference and achieving trustworthiness. These are listed below.

1. Triangulation. We conducted data collection using interviews and medical record review, to explore the experiences of pregnant women with cancer in decision-making from both subjective and objective perspectives. This could contribute to the understanding of contexts that may not be sufficiently expressed in words.
2. Peer review. We conducted analyses using more than two researchers to enhance the credibility and dependability of this qualitative research. The first author was a doctoral student who worked in obstetrics and gynecology as a midwife and nurse; the second and third authors were researchers in cancer nursing. The first author collected the data, and the first and second authors held discussions about developing codes, subcategories, categories, themes, and phases during and after analysis, and revised these so as to obtain a consensus. The third author played the role of auditor.
3. Negative case analysis. We also conducted a negative case analysis by comparing negative cases with the norm or the most commonly occurring cases and considering cause and effect on the experience of participants. This would be helpful in understanding the meaning embedded within the context and to improve the inference accuracy.

2.3 | Ethical considerations

This study was conducted with the approval of the ethics committee at Graduate School of Nursing, Chiba University. All participants were assured anonymity and confidentiality by the researchers. One-on-one interviews were conducted at a location that ensured privacy. The researchers emphasized that the participant was free to decline participation in the interview.

2.4 | Participants

Women were eligible for inclusion if they had been diagnosed with cancer and had made any treatment decisions during pregnancy; if at least 1 month had passed after the end of their pregnancy (this included both artificial abortion and live birth) and the end of the primary treatment for cancer; and if the participant had been judged by her doctor to have no mental disorder.

There were 15 eligible Japanese women who met all inclusion criteria. These women were sent a letter of invitation to participate and nine responded. One woman declined to participate in the study owing to concerns about anonymity. Finally, eight women were included in the study.

2.5 | Recruitment and setting

Recruitment was conducted at one university hospital with an obstetrics department, NICU, specialists for all cancers, and a psychiatry department. This hospital is located in an urban area of Japan and is one of the country's largest hospitals with more than 800 beds. All eligible women were selected from the hospital delivery registry between 2005 and 2011 and were sent an invitation to participate in our study at an upcoming medical checkup. If women were interested in receiving more details about the study, they were asked to contact a researcher, who then explained the research outline; individuals could then consent to take part in the study. Data collection was carried out from June 2011 to January 2012.

2.6 | Data collection

All participants were asked to give consent for a researcher to review their medical records before the interview, to obtain information about each case including family history, diagnosis, staging, examination results, treatment progress, and obstetric history. Researchers conducted one semi-structured interview with each participant. Permission was given by participants to audiotape the interviews, and the audiotaped interview data were then transcribed. After each interview, the participant's medical records were reviewed again, to understand how each participant's decision-making process developed.

Interview questions aimed to collect information on the situation at the time participants were diagnosed with cancer during pregnancy, the progress of medical treatment, the participant's decision-making process, and the participant's feelings after decision-making.

2.7 | Analysis

We conducted an analysis of the data using the following procedures, with reference to the qualitative content

analysis of Krippendorff (1980), and Graneheim and Lundman (2004).

1. We repeatedly examined the data for each participant and extracted those portions involved with participants' experiences of the decision-making process.
2. We refined and reconstructed each participant's experience of the decision-making process, taking into account the passage of time so as to permit better understanding without compromising meaning. We denoted this as the text of the decision-making experience.
3. We confirmed consistency between each participant's text of the decision-making experience and the medical record. If these were inconsistent, we treated the medical record data as complementary.
4. We divided all participants' texts of their decision-making experiences into units of meaning and denoted these as codes.
5. We sorted all participant codes into subcategories according to similarity.
6. We sorted all subcategories into categories according to similarity.
7. We sorted all categories into themes according to similarity.
8. We sorted all themes into phases considering the events, meanings, and psychological processes involved in decision-making.

3 | RESULTS

3.1 | Participants

Participant information and an outline of the decision-making process are shown in Table 1. All eight participants were diagnosed with cancer during pregnancy: three women were diagnosed with cancer before they knew they were pregnant, and five were diagnosed with cancer after they knew about their pregnancy. Participant A was diagnosed with cancer during the second trimester, and the other participants were diagnosed with cancer in the first trimester.

There were three women with cervical cancer, two with breast cancer, two with leukemia, and one with digestive cancer. The average participant age was 35.5 years and the average time after childbirth or abortion at the time of the interview was 14 months (range 4–28 months). Of the eight participants, four women had no children when they were diagnosed with cancer and four had one or two children at the time of diagnosis.

The contents of decision-making included the following: six women had to decide whether to continue their pregnancy or have an abortion, three women chose when to give birth, two women chose the surgery method performed while pregnant, and one woman decided to have a hysterectomy. Some women made multiple decisions throughout their pregnancy.

Participants' pregnancy outcomes were as follows: two women had an abortion, two gave birth prematurely, and four women had full-term births. All women survived with no recurrence at the time of the interview. Six women underwent cancer treatment during their pregnancy including breast surgery, chemotherapy, and cervical conization. All women received cancer treatment after their pregnancy including chemotherapy, surgery, and radiotherapy. There were no patients referred to the psychiatry department.

3.2 | Experiences of pregnant women with cancer in decision-making

The experiences of eight women were transcribed into 118 codes; these were subsequently sorted into 56 subcategories, 14 categories, and seven themes. Finally, the seven themes were sorted into three phases. Table 2 lists the phases, themes, and categories. Each phase and theme is explained below. Items with italics refer to a theme and those marked within double quotes “ ” refer to a code.

3.3 | Interaction between the woman and her fetus, family members, and medical staff

The first phase of experiences among pregnant women with cancer in decision-making included confusion about the overlap between cancer and pregnancy, and discussions with medical staff and family members. This phase involved the communication between pregnant women and their families and medical staff, which formed the basis for decision-making. The fetus was important for pregnant women, but this remained obscure and subordinate in communication with their surroundings. If the fetus was respected, the pregnant woman could gain strength; otherwise, she would feel isolated.

3.3.1 | Confusion arising from being diagnosed with cancer during pregnancy

This theme expresses women's confusion about the diagnosis and involvement of medical staff such as from transferring hospitals while in shock over the cancer diagnosis.

Seven participants who were transferred to a hospital described the experience of this theme. They met with medical professionals such as oncologists and obstetricians in rapid succession, which increased their confusion. At this time, participants experienced difficulty in processing information on cancer treatment and obstetric care owing to the impact of the cancer diagnosis.

TABLE 1 Participant information and an outline of the decision-making process

Participant information	Outline of the decision-making
A Cervical cancer[a] Multipara[b] Abortion[c]	The doctor suggested that the patient should have an abortion and undergo complete hysterectomy immediately, or wait for 10 weeks with continuous pregnancy and undergo cesarean section simultaneously with total hysterectomy at 28 weeks of gestation. The patient had a desire to continue the pregnancy, but her mother and husband opposed this. She thought it would be a pity if the baby had a disability owing to preterm birth, and she finally decided on abortion. She explained that she regretted that she did not express her desire to continue her pregnancy, and that she did not have time to collect information on the effects of chemo on the fetus.
B Leukemia[a] Multipara[b] Abortion[c]	The doctor strongly recommended that the patient abort immediately and start chemotherapy. She had a desire to continue pregnancy but her mother and sister opposed this. She agreed to abortion, fearing that the effects of chemotherapy would cause fetal damage. She explained that she could not take care of her other children and had to follow the views of her mother and sister, and that she had no time to find a doctor who could treat her while continuing her pregnancy.
C Digestive cancer[a] Primipara[b] Premature birth[c]	The doctor suggested that the patient should either abort immediately and undergo surgery, or continue the pregnancy on the condition of surgery if the cancer worsened suddenly. She decided to continue her pregnancy. The doctor recommended preterm delivery at 28 weeks of gestation, but she was concerned about the risk of preterm birth and did not agree. She decided to give birth at 34 weeks of gestation and to have surgery soon after delivery. She explained that she was anxious about the progression of cancer but she tried to think it was all right to give birth to a child.
D Breast cancer[a] Primipara[b] Live birth[c]	The doctor suggested that the patient have a partial mastectomy during pregnancy and offered general anesthesia or local anesthesia as an option. She chose partial mastectomy with local anesthesia. She explained that she was lucky to have surgery under local anesthesia because her child was more important than breast cancer.
E Leukemia[a] Multipara[b] Full-term birth[c]	The doctor explained to the patient that molecular-targeted drugs cannot be used during pregnancy, so if she wanted to continue pregnancy she will need to use interferon to treat the disease. She and her husband decided to continue the pregnancy. She explained that she thought that she would not give up because it was her last pregnancy and she also believed in the effectiveness of molecular-targeted drug therapy started after delivery.
F Cervical cancer[a] Primipara[b] Premature birth[c]	The pathology results after cervical conization indicated adenocarcinoma and were positive for cervical stump cancer. The doctor suggested that the patient should either abort immediately and have a total hysterectomy, or she should have a cesarean section at 28 weeks of gestation and simultaneous total hysterectomy. She and her husband decided to continue the pregnancy because this was her last pregnancy. They negotiated with doctors to wait until 34 weeks of gestation for the baby's lungs to mature. The doctor gave permission to continue pregnancy on condition that she have a cytology every time and give birth as soon as any abnormality occurs. She explained that she was afraid of cancer progression but did not think about it so seriously.
G Cervical cancer[a] Primipara[b] Full-term birth[c]	The patient's cancer was in the early stages, so she was followed up without treatment. The doctor suddenly recommended a cesarean section at 36 weeks of gestation and a total hysterectomy the next week. Both she and her husband were shocked but agreed. She explained that she tried to think this was good because she and her baby would be all right. But when she heard that her friend gave birth to another child, she regretted that she did not have better discussions with her doctor on how to avoid a total hysterectomy.
H Breast cancer[a] Multipara[b] Full-term birth[c]	The doctor explained all the tests and treatments for breast cancer, some of which were not possible during pregnancy. The patient considered abortion as an option, but she could not make a decision about abortion and decided to have a mastectomy at 18 weeks of gestation. At 22 weeks of gestation, she could no longer think about killing her baby and decided to continue her pregnancy. The doctor advised her to start chemotherapy from 25 weeks of gestation and she agreed. She explained that it was good for her to limit her treatment options because she had so many options that it was difficult to decide.

[a]Cancer type.
[b]Primipara or multipara.
[c]Pregnancy outcome.

"My head was full of cancer rather than considering whether I continued or not my pregnancy." (Participant A)

3.3.2 | Discussions with doctors so as to make the best informed decision

This theme expresses the great effort required by women to obtain the best and most information and options from medical staff regarding continuing their pregnancy and cancer treatment.

This theme arose from the experiences of participants C and F who were recommended an abortion or to have a premature birth by their doctor so as to rush cancer treatment and participant H who considered abortion an option. Various challenges were mentioned, such as difficulty obtaining information about other options if the patient did not agree

TABLE 2 Experience of Jananese pregnant women with cancer in decision-making; the three phases, seven themes and 14 categories

Phase	Theme	Category
The interaction between the woman and her fetus, family members, and medical staff	Confusion arising from being diagnosed with cancer during pregnancy	Experiencing extreme stress both physically and mentally after receiving the diagnosis
	Discussions with doctors so as to make the best informed decision	Strong desire to negotiate other options in cases where doctors advise women to prioritize cancer treatment over the pregnancy
		Wanting access to any relevant information on cancer treatment during pregnancy so as to be able to consider all options
	Being influenced by the opinions of family members in choosing whether to continue the pregnancy and cancer treatment options	Being persuaded to prioritize cancer treatment over the pregnancy by family and friends
		Not being able to fully express complex feelings to family members and feeling as if they were going through the process alone
		Feeling their family and friend's support, understanding, and kindness
Confrontation with dilemma and uncertainty	Inner conflict over whether to prioritize their own life or that of their fetus	Agonizing over the distressing decision of whether to continue the pregnancy
		Having difficulty deciding whether to risk their child's health or risk their own cancer progressing
	Lingering uncertainty throughout the course of cancer and pregnancy	Feeling stress owing to uncertainty about the future with respect to the pregnancy and cancer
Redefinition of the women's own decisions	Relief after deciding to continue their pregnancy and having reduced fear of cancer and treatment	Prioritizing the pregnancy over cancer
		Finding positive aspects about being a pregnant cancer patient
		Avoiding thoughts about cancer and treatments
	Regrets about decisions made regarding cancer treatment that results in loss of fertility and termination of pregnancy	Continuously remembering the time they felt forced into making a decision they regretted about terminating pregnancy and the lack of information and/or time they had to consider it
		Distrust of a health professional because of a lack of information

with the advice of a doctor, and dealing with young male doctors who could not relate to their situation of giving birth with cancer. Participants wanted to have as much choice and information as possible. However, when talking to physicians about abortion and preterm labor, they experienced difficulty in having frank discussions, feeling psychological and social resistance owing to threatened social norms.

"The doctor suggested that I give birth prematurely and explained the risks to the baby, but I couldn't agree with him immediately." (Participant C)

3.3.3 | Being influenced by the opinions of family members in choosing whether to continue the pregnancy and cancer treatment options

This theme expresses the aspect of how communication with family members about choosing to continue pregnancy or cancer treatment affected participants' self-disclosure and decision-making.

Six participants were persuaded by their family or friends to prioritize themselves over their fetus or their fertility. All six women did not interpret the advice to care for themselves as a positive message. Their experience was of receiving the message to ignore the life and health of the fetus from their families.

"My husband and my best friend told me to prioritize my healing rather than the baby's life." (Participant H)

Except for participants A and B who had an abortion, six participants exchanged their thoughts, ideas, and feelings with their husbands. Women who were accompanied by their husbands to medical appointments felt that they received support from them. They experienced gratitude for being able to make decisions while sharing their feelings with their husbands.

"My husband was worried but understanding me about accepting a hysterectomy because we got really shock about it." (Participant G).

Participants A and B thought that it was difficult to share their own opinion because family members had counseled them to give up the fetus. Participant C gave her husband only basic information and thought that it became more difficult to explain the complicated situation with the advancement of their pregnancy. These women experienced a sense of solitude and anxiety, and a loss of power to convey their thoughts to their families.

"All other family members opposed me continuing my pregnancy. I thought that nobody but me could understand this situation because they weren't pregnant." (Participant B)

"I did not know what to say when my husband asked if I was okay." (Participant C)

3.4 | Confrontation with dilemma and uncertainty

The next phase included dilemma and uncertainty about self and fetal health. This phase was the internal work of the pregnant woman and was the final confirmation of their decision-making. The fetus represented a human life to the pregnant women. Owing to the presence of the fetus, pregnant women experienced increased or decreased suffering from cancer and treatment.

3.4.1 | Inner conflict over whether to prioritize their own life or that of the fetus

This theme expresses the conflict of whether women should give priority to themselves or their fetus. These women were forced to ponder the compatibility of cancer and pregnancy, as well as the possibility of exposing their fetus to the risk of health problems owing to premature birth or drug exposure in utero, and these in the face of their own risk of cancer progression.

This theme was based on the experiences of participants A, B, C, and H who considered abortion and premature birth. At first, all four participants wanted to continue their pregnancies. They were subsequently informed by their doctors that they should receive anti-cancer drug treatment and/or have a premature birth, which could expose the fetus to risks that could lead to disorders. The women reported asking themselves whether it would be possible for them to care for their child if it were born with disabilities and if they had cancer. These participants expressed concern at delaying cancer treatment because it could result not only in progression of their disease but would also disrupt care of the infant and her other children. The women described conflict between their own risk of cancer progression and risk of their fetus being born with health problems or a disability. Participants experienced hope for their health and that of their fetus as well as fear of impairing their own health or that of their fetus.

"If I disagree with premature birth, it means a delay in cancer treatment, I would fall ill. If I fall ill, I can't take care of my child. The mere thought of it troubles me deeply. This decision-making was quite difficult for me." (Participant C)

3.4.2 | Lingering uncertainty throughout the course of cancer and pregnancy

This theme expresses the concern of whether participants will be able to give birth or whether the cancer will progress if they decide to continue the pregnancy.

This theme was created by the experiences of participants C and F who decided to continue their pregnancy under the condition that they would have an abortion if there was an acute exacerbation of their cancer. They described troubling feelings of anxiety and fear that the cancer would progress if they received no treatment, anxiety about terminating their pregnancy versus having a normal childbirth and healthy baby, and anxiety about what might happen for their husband if their cancer progressed and they could no longer have children. Pregnant women with cancer who were advised to have a preterm birth had to deal with uncertainty as a result of their decision to continue their pregnancy.

"The most anxious and painful thing involved what would happen if I could not give birth." (Participant C)

"I was afraid that the cancer may have still been spreading but I did not know because there was no pain." (Participant F)

3.5 | Redefinition of the women's own decisions

The final phase included the value of the pregnancy or regret during the decision-making process. This phase was a reflection, meaning reflection on their decisions and assessing their own commitment to their decisions.

3.5.1 | Relief after deciding to continue their pregnancy and having reduced fear of cancer and treatment

This theme expresses the experience of finding meaning in light of the reality of having cancer while pregnant, and joy at continuing the pregnancy and putting cancer and treatment aside until after childbirth.

All six participants who continued their pregnancy experienced this theme. Although the meaning of prioritizing their pregnancy varied for each woman, what was common

to all six participants was the belief that the current pregnancy was their last chance to experience childbirth. In response to any remaining uncertainty, these participants experienced the desire for the cancer not to progress and a devotion to the health of their child until it was born.

"As for me, I decided to have a hysterectomy after childbirth because I had adenocarcinoma, so I did not expect to give up on this pregnancy." (Participant F)

3.5.2 | Regrets about decisions made regarding cancer treatment that results in loss of fertility and termination of pregnancy

This theme expresses what participants felt were the causes of regret and distrust, that they were unable to discuss options with family and medical staff or have enough time to collect more information because of the urgency of pregnancy overlapping with cancer.

This theme mainly reflected the experiences of participants A, B, and G. These participants continuously recalled their reluctance to terminate their pregnancy whenever they heard that someone had given birth to another child. They debated with themselves the pros and cons of their abortion or hysterectomy and their decision-making process, especially if there was little involvement of family and medical staff. Participants experienced feeling regret that they did not have the power to ask doctors and family members for more time and information to make a decision.

"If I had had one more week, I could have gathered enough information about the influence of chemotherapy on the fetus." (Participant A)

"The doctor explained that cesarean section and radical hysterectomy will be performed at the same time next week, and I felt that there was no choice." (Participant G)

4 | DISCUSSION

This study revealed that decision-making in pregnant women with cancer results from interaction between the fetus, medical staff, and family members as well as confrontation with dilemma and uncertainty, and redefinition of the women's own decisions continues after decision-making. From our results, the experience of decision-making in Japanese pregnant women with cancer can be understood in terms of three phases. The first phase refers to verbal and nonverbal communication with their surroundings, and the second and third phases indicate reflection, such that the experience of decision-making among Japanese pregnant women who have cancer can be summarized as having two aspects: communication and reflection.

The first aspect, verbal and nonverbal communication, is derived from the phase of interaction between the woman and her fetus, family members, and medical staff. The present research revealed the situations in which pregnant women with cancer often cannot successfully exchange their feelings and information. These situations include when they are confused by the cancer diagnosis or a hospital transfer, when having an abortion or premature birth is an option, and when they receive messages to ignore the fetus when the woman's health is threatened. These situations seem to arise owing to when nonverbal communication between the woman and fetus and verbal communication between the woman and the family and medical staff is inconsistent. According to results of this research, in these scenarios, pregnant women with cancer felt a sense of solitude and anxiety and felt unable to express their feelings and informational needs. We also found that making decisions without being able to express feelings or informational needs led to feelings of regret in these women. The sense of solitude and anxiety in our study population seemed to arise from the recognition that no one can understand, support, or solve problems that arise from having a pregnancy and cancer at the same time. This indicates that there were no medical staff from whom pregnant women with cancer recognized that they could receive assistance. This represents an absence of medical professionals who understand, support, and think about solutions for these women. Our study findings highlight the need to provide continuous communication channels and frank dialogue for pregnant women with cancer.

The second aspect, reflection, is derived from the phase of confrontation with dilemma and uncertainty, and redefinition of the women's own decisions. This research revealed that conflicts and uncertainty remain, regardless of the level of satisfaction or dissatisfaction with decisions made. This seems to be because no one can guarantee the health of the woman or the fetus owing to exposure in the uterus to cancer treatment, delayed cancer treatment, or premature birth. According to our results, pregnant women with cancer greatly valued their pregnancies and diminished the cancer threat to relieve conflict and uncertainty. In addition, we found that women who decided to have an abortion or premature birth experienced suffering and regretted that they had not expressed their thoughts and informational needs earlier. This study highlights the need to understand and support the unique experiences and unmet needs of pregnant women who have cancer. With proper psychological care, these women can regain power so as to make decisions that are right for them, through receiving individualized information and assistance from multidisciplinary teams of experts as a next step.

4.1 | Clinical implications

The role of nurses in providing care to pregnant women with cancer for decision-making is twofold. The first is to guarantee that these women have access to continuous channels of communication and to offer opportunities for open dialogue. Nurses should allow women to be frank rather than impose their own values and ethics. Women in a state of confusion or insecurity about being diagnosed with cancer during pregnancy find it difficult to correctly understand the information provided by physicians such as obstetricians and cancer specialists, as well as to think about and integrate the information and consider how to discuss it with family. Nurses should engage in frank dialogue with these women, so that they can cope with difficult situations.

The second role of nurses is to empower pregnant women to express their own thoughts and informational needs to medical staff and to their family. It is important that nurses and pregnant women together consider problem-solving methods for issues of communication with other individuals, informational needs, and psychosocial challenges owing to dilemma and uncertainty. If pregnant women have symptoms of mental distress, such as sleeplessness or depression, referral to a psychiatrist will be helpful. With such continued support, these women will be able to make the best use of the information and care provided by multidisciplinary teams.

4.2 | Limitations

This study was conducted at one university hospital in an urban area of Japan. This hospital has an obstetrics department, NICU and all cancer specialists. However, this limits the generalizability of our findings and evaluation of thematic saturation. Because all participants were Japanese, our findings might be specific to Japanese women with respect to involvement of family members in decision-making, the nature of the doctor–patient relationship, and access to information in English. Furthermore, a significant feature may be that in Japan, abortion is permitted until 22 weeks of pregnancy.

We had a small cohort of eight women with varying cancer types and obstetric outcomes. It might therefore be difficult to apply these results to all pregnant women with cancer. There is a possibility of selection bias because there were eight participants from 15 candidates, and all eight participants had disease-free survival; therefore, our study participants may feel happy with their decision-making. In addition, there is a possibility of memory bias owing to ambiguous recall of information because participants were interviewed at 9 months (the shortest time) to 3 years after cancer diagnosis (the longest time). However, this period might be needed for women to be able to appraise their decision-making process themselves; the findings of this study could help to clarify those feelings.

In conclusion, this study aimed to clarify the experience of pregnant women with cancer in decision-making, and the findings could have important implications for nurses. Such impacts should be verified in future studies.

4.3 | Conclusion

This study revealed that decision-making in pregnant women with cancer results from interaction among the fetus, medical staff, and family members as well as confrontation with dilemma and uncertainty, and redefinition of the women's own decisions continues after decision-making. From our results, the experience of decision-making among Japanese pregnant women with cancer can be understood as constituting three phases. We considered that the first phase refers to verbal and nonverbal communication with their surroundings, and the second and third phases indicate reflection.

The role of a nurse is to guarantee open communication channels and dialogue, and to empower these pregnant women to express their thoughts and informational needs to medical staff and their family members.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

AUTHORS' CONTRIBUTIONS

M. K. designed the study and carried out the data collection; M. K. and M. M. conducted the data analysis; M. K. drafted the manuscript; and T. M. critically reviewed the manuscript and supervised the whole study process. All authors read and approved the final manuscript.

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