





## Barriers to and Facilitators of Shared Decision-Making Implementation in Fertility Preservation for Patients With Cancer: A Qualitative Study

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#### **ABSTRACT**

**Introduction:** To identify the barriers and facilitators in the implementation of fertility preservation (FP) shared decision-making (SDM) in oncology care.

**Design:** Qualitative descriptive study.

**Methods:** Qualitative interviews with 16 female patients with cancer and seven healthcare providers were conducted between July 2022 and April 2024. Data were analyzed using directed content analysis, guided by the implementation science framework. **Results:** We identified 22 categories comprising 38 codes as barriers to SDM implementation and 17 categories comprising 26 codes as facilitators. Findings revealed that, at the innovation level, accessibility, feasibility, interdisciplinary collaboration, and quality improvement efforts were decisive in the implementation of FP SDM. At the individual level, healthcare providers' awareness and attitudes towards FP and SDM, as well as patients' knowledge, attitudes, and capabilities in FP SDM, were crucial factors in the implementation of FP SDM. In social, economic, and organizational contexts, support from significant others, social awareness about FP, multidisciplinary care, financial assistance, and educational resources were determinants in implementing FP SDM.

**Conclusion:** Implementing FP SDM among female patients with cancer necessitates a strategic approach that considers barriers and facilitators. Educating and promoting FP SDM among the public and healthcare providers, combined with incentivizing policies, can enhance individual knowledge and awareness while achieving systemic improvements, facilitating its successful implementation.

**Clinical Relevance:** This study provides insights into barriers and facilitators and proposes strategic approaches to enhancing FP SDM implementation, contributing to improved quality of life for cancer survivors and advancements in clinical practice.

#### 1 | Introduction

Recently, cancer incidence among adolescents and adults aged 15–39 has been increasing continuously (Cronin et al. 2022),

leading to increased cancer diagnoses during reproductive years. Fortunately, advancements in medical technology have resulted in decreased mortality and improved survival rates, shifting the focus of oncology nursing from treatment-centered

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strategies to survivorship (Chen et al. 2022). Infertility caused by cancer treatments such as chemotherapy and radiotherapy poses a significant issue for cancer survivors, inducing psychological distress and impairing their long-term quality of life (Patterson et al. 2021). Therefore, international oncology guidelines recommend providing timely information about fertility preservation (FP) to all reproductive patients considering gonadotoxic treatments (Lambertini et al. 2020).

Decisions regarding FP must consider medical factors and patients' personal preferences and circumstances. Therefore, shared decision-making (SDM) involving patient participation is highly emphasized. SDM treats patients as equal partners, respects their autonomy, and supports them in making informed and voluntary decisions (Amir et al. 2021). This approach involves clinicians and patients sharing the best available evidence and supporting patients in considering and choosing available alternatives based on their values and preferences (Abbett et al. 2020). The FP SDM process for patients with cancer involves multiple steps, with various healthcare providers participating at each stage (Anazodo et al. 2019). Before starting cancer treatment, oncologists assess the risk of infertility and discuss it with patients, referring those interested in FP to fertility specialists (Preservation et al. 2020). A patient consults with a fertility specialist to decide whether to proceed with FP and what methods to use; if desired, FP is performed. The patient then returns to the oncology department to begin cancer treatment. Thus, patients with cancer encounter different healthcare providers throughout their diagnosis and treatment processes, and a multidisciplinary team conducts FP SDM (Pathak et al. 2023). If a hospital lacks fertility specialists or cannot perform FP, the patient must visit additional healthcare institutions, further complicating the situation.

Several FP options are available for patients undergoing gonadotoxic treatments. For female patients, oocyte and embryo cryopreservation are widely used, requiring ovarian stimulation and egg retrieval (Oktay et al. 2018). Ovarian tissue cryopreservation is an emerging technique that preserves ovarian tissue containing numerous follicles, making it a potential option even for prepubertal girls (Bahroudi et al. 2022). GnRHa temporarily suppresses ovarian function during chemotherapy, potentially helping protect the ovarian reserve; however, its effectiveness is debated (Razeti et al. 2021). For male patients, sperm cryopreservation is the primary method (Tran et al. 2022). These FP options provide patients with post-treatment reproductive choices and highlight the need for informed decision-making through SDM.

For female patients, the FP process is more complex than that for males and requires time for oocyte or embryo cryopreservation, raising concerns about delays in cancer treatment (Kappy et al. 2021). Thus, FP is considered an emotionally and physically challenging process for female patients (Wang et al. 2020), highlighting the need for support in SDM, specifically for women. Regardless of whether FP is pursued, SDM has been shown to alleviate fertility-related distress (Wang et al. 2020), making its implementation particularly crucial. Moreover, it is estimated that over 100 million women worldwide will be at risk of cancer treatment-related infertility by

2025 (Sun and Yeh 2021). Given the increasing demand for FP SDM, research on its implementation must be conducted promptly to ensure its effective integration into clinical practice.

To address this need, several studies related to FP SDM have been conducted. Nonetheless, approximately 30%–50% of patients do not receive adequate information about infertility risks and FP options prior to initiating cancer treatment (Coker Appiah et al. 2021). Furthermore, a meta-analysis of FP SDM indicated that only a few studies have considered its sustainability within the healthcare system (Pathak et al. 2023), hindering its effective implementation. Understanding the motivations for and resistance to successful SDM implementation is critical for developing strategies to improve its uptake (Tang et al. 2022).

While the widespread recognition of the importance of FP SDM, its accessibility and uptake remain low in real-world settings (Pathak et al. 2023). To overcome these challenges, it is crucial to gain insight into the barriers and facilitators, develop implementation strategies that overcome these barriers, and enhance the facilitators to increase the uptake of evidence-based clinical innovations (Bauer and Kirchner 2020). Implementation science (IS) is the scientific study of methods and strategies used to promote the integration of research findings and evidence into healthcare policies and practices (Roberts et al. 2023). IS can be applied to SDM because it provides a systematic approach to identifying and addressing the complexities in integrating SDM into clinical practice. IS can help bridge the gap between scientific evidence and patient care, facilitating effective and sustainable integration of FP SDM into clinical practice. An implementation framework provides a structured method for identifying, analyzing, and addressing the factors influencing the implementation of interventions in healthcare settings (Moullin et al. 2020). However, previous studies have primarily identified the barriers and facilitators related to FP decision- making (Di Mattei et al. 2021; Dorfman et al. 2021). Few studies have focused on the implementation of FP SDM using an IS framework. Knowledge on how to adopt and implement SDM in practice can contribute to raising awareness of the significance of FP SDM in cancer care.

The aim of this paper is to identify the barriers to and facilitators of FP SDM implementation to bridge the research-to-practice gap and generate insights that can improve clinical practice.

## 2 | Materials and Methods

## 2.1 | Aim of the Study

This study's purpose was to identify barriers and facilitators when implementing FP SDM in female patients with cancer across multiple context levels, using Grol and Wensing's (2004) implementation framework. The findings will be used to develop strategies to enhance the successful uptake and dissemination of FP SDM in clinical practice and provide insights related to IS.

### 2.2 | Design

This qualitative study aimed to identify barriers and facilitators in the implementation of FP SDM in oncology care from female patients' and healthcare providers' perspectives.

#### 2.3 | Conceptual Framework

This study explored the barriers to and facilitators of FP SDM based on the framework proposed by Grol and Wensing (2004). This framework describes how to identify, categorize, and utilize barriers and incentives for the successful implementation of evidence. The framework employs a multi-level approach to examining barriers and incentives for change at six levels: the innovation itself, individual professional, patient, social context, organizational context, and economic and political context. In this study, we explored and categorized barriers and facilitators and suggested strategies based on these findings according to the six levels (Table S1).

## 2.4 | Study Setting and Recruitment

This study included female patients with cancer and healthcare providers to comprehensively examine the barriers to and facilitators of FP SDM. Female patients with cancer were recruited by posting documents in online communities, with permission from community administrators. Interested individuals directly contacted the researchers and were screened for eligibility. The researchers purposefully selected participants who could provide rich experiences. Based on prior studies involving 12 to 21 participants (Bentsen et al. 2023; Dahhan et al. 2021; Del Valle et al. 2022), this study aimed to collect data from approximately 15–20 patients with cancer, continuing until theoretical saturation was achieved.

Healthcare providers were recruited through purposeful sampling that included recommendations from relevant professional societies and direct contact with individuals with extensive research and/or clinical experience in FP. Emails explaining the study's purpose and procedures were sent to the experts, and those who voluntarily agreed to participate were recruited. This approach aimed to involve healthcare providers from various medical institutions, specialties, and professional roles.

### 2.5 | Inclusion and/or Exclusion Criteria

The patient group for this study included the following: (1) female cancer survivors aged between 18 and 45 years; (2) those who had received gonadotoxic cancer treatment; (3) patients not undergoing active treatment such as surgery, chemotherapy, or radiotherapy; (4) individuals without cognitive impairments and able to communicate; (5) those who agreed to participate in the study. Patients were excluded if they (1) had a previous cancer history before their current cancer, (2) experienced cancer recurrence, or (3) received infertility treatment prior to their cancer diagnosis.

Seventeen female patients expressed willingness to participate; however, one was excluded because of prior infertility treatment, resulting in 16 participating patients. These participants were aged between 28 and 41 years, comprising 11 unmarried and five married individuals. The participants were predominantly women diagnosed with breast cancer who had received chemotherapy. The majority chose to undergo FP, including gonadotropin-releasing hormone (GnRH agonist) therapy, whereas three participants opted for FP (Table S2).

The healthcare provider group included professionals involved in counseling and treatment related to FP in patients with cancer. Seven healthcare providers were invited through recommendations or direct outreach, and they all agreed to participate. The group included one breast surgeon, four fertility specialists, and two fertility specialist nurses.

#### 2.6 | Data Collection

Data were collected from July 2022 to April 2024 through individual in-depth interviews via telephone or Zoom. Semi-structured interview questions (Table S3) were developed during three research meetings based on relevant existing studies (Hoffman et al. 2021; Salsman et al. 2021) and the clinical and research experience of the researchers. Two female researchers (JH and JA) with extensive expertise in qualitative research on female patients with cancer conducted the interviews. Each participant was interviewed once, with interviews lasting 60–90min for patients and 30–60min for healthcare providers. During the interviews, field notes were documented for verbal and nonverbal expressions that reflected the participants' emotions. After interviewing 16 patients and seven healthcare providers, the study met its target number of participants, and all researchers agreed that theoretical saturation was achieved, concluding the interview process.

#### 2.7 | Data Analysis

A directed content analysis method (Hsieh and Shannon 2005) was used to systematically analyze the data and identify their patterns based on the existing theoretical framework—the IS framework (Grol and Wensing 2004). Each key concept and variable from the framework was used as the initial coding system and defined. The research team transcribed and thoroughly reviewed all the recorded interviews multiple times. Subsequently, they highlighted the text relevant to the research question and assigned it to the initial code. These codes were categorized based on the theoretical framework levels and factors identified by Grol and Wensing (2004). New ideas or concepts that could not be categorized under the existing categories and codes were assigned new codes or reinterpreted to determine whether the current coding system required further adjustments. This approach allowed us to analyze the data in a more structured manner under various levels that impact the complex nature of implementation. Any discrepancies in coding among the research team members, as well as the final categories and codes, were discussed and resolved in multiple team meetings. MAXQDA 24 software was used for data analysis.

## 2.8 | Ethical Considerations

This study was approved by the Institutional Review Board of Chung-Ang University where the study took place before data collection (IRB No. 1041078-202203-HR-101), with approval granted on May 30, 2022. Before conducting the interviews, the participants received detailed explanations regarding the study's objectives, procedures, and the option to withdraw voluntarily. Written informed consent was obtained from each participant to ensure voluntary participation. Interviews were recorded with participants' consent, and personal identifiers were encrypted during transcription to guarantee anonymity. Participants were compensated appropriately to appreciate them for their participation in the study.

## 2.9 | Rigor and Reflexivity

This study ensured rigor based on the criteria of truth value, applicability, consistency, and neutrality (Guba and Lincoln 1981). First, to meet the truth value, participants who could best describe the research phenomena were selected and encouraged to express their experiences freely. At the end of the interviews, the researchers confirmed the main content with the participants to ensure that their experiences were accurately understood and reflected. Second, the participants' characteristics were presented to enhance their applicability. Third, to ensure consistency, the data were analyzed and results derived according to the method proposed by Hsieh and Shannon (2005), with the entire process documented in detail. Fourth, to establish neutrality, the researchers maintained a neutral stance and made efforts to analyze the participants' perspectives.

## 3 | Results

# 3.1 | Barriers and Facilitators Influencing Implementation of FP SDM

We identified 22 categories comprising 38 codes as barriers to SDM implementation (Table 1) and 17 categories comprising 26 codes as facilitators (Table 2).

#### 3.2 | Innovation in the Implementation of FP SDM

Innovation in FP SDM implementation primarily stemmed from healthcare providers, with three key categories emerging as barriers: low accessibility, low feasibility, and lack of interdisciplinary collaboration. Low accessibility resulted in patients not receiving the FP information from healthcare providers, rendering SDM implementation impossible. Additionally, the low feasibility stemming from time constraints due to cancer treatment was exacerbated by faster cancer progression and higher cancer stages. Another identified barrier was the lack of interdisciplinary collaboration, evident in insufficient communication between the oncology and fertility teams, along with the transfer of SDM responsibility between them.

Three categories emerged as innovation facilitators: sufficient accessibility, sufficient feasibility, and continuous quality improvement efforts. Facilitators for SDM implementation were found to be sufficiently accessible, as evidenced by patients

selecting institutions or doctors where SDM was accessible and utilizing digital technology to enhance accessibility. Additionally, sufficient feasibility was identified as a facilitator, with detailed codes such as respect for patient decisions, alleviation of psychological burdens, and inter-professional collaboration. Finally, verifying patients' decision outcomes, such as decision regret, as part of continuous quality improvement efforts, also emerged as a facilitator.

#### 3.3 | Individual Professional

Individual professionals emerged from both the oncology and fertility teams, highlighting their respective roles in the SDM process as it transitioned between the teams.

#### 3.3.1 | Oncology Team

The primary barrier within the oncology team was identified as a lack of awareness towards FP. This has led to the misconception that FP is unnecessary outside of cancer treatment or for patients with advanced cancer stages or existing children, suggesting a prejudgment against the need for FP. Furthermore, in some cases, referrals to fertility clinics have been made without explanations regarding fertility decline or FP.

Conversely, the facilitators included an oncology team with positive attitudes who initiated discussions by first asking about patient values and preferences. They engaged in transparent and clear communication regarding fertility decline or preservation and provided empathetic support along with proactive referrals.

#### 3.3.2 | Fertility Team

Barriers within the fertility team included passive attitudes. Fertility specialists sometimes make decisions without considering a patient's voice, providing explanations only for the options they deem suitable without discussing various alternatives. Furthermore, they proceeded with the procedures without verifying how well the patients understood the various methods.

Sufficient awareness has emerged as a facilitator of SDM implementation within fertility teams, providing patients with ample opportunities to make deliberate decisions.

## 3.3.3 | Patient With Cancer

Barriers at the patient level encompass several factors, including a lack of basic understanding of fertility decline and preservation, difficulty in communication about FP, passive attitudes towards FP SDM, and psychological burden of decision-making. Patients experienced challenges in performing SDM owing to their lack of understanding of fertility decline and preservation. Additionally, they encountered difficulties in communicating about FP. They were not prepared to ask questions about FP and lacked opportunities to participate in active discussions. Furthermore, a passive attitude towards FP SDM emerged as

 $\textbf{TABLE 1} \quad | \quad \text{Barriers influencing implementation of SDM in fertility preservation.}$ 

| Level                         | Category and code  | Example quote  |
|-------------------------------|--|--|
| Innovation                    | Low accessibility  |  |
|                               | No opportunity for SDM   | Patients at other hospitals receive treatments like egg freezing or ovarian protection injections alongside their cancer therapy. However, I didn't hear about these options. If they had informed me about the potential infertility due to chemotherapy, it would have made a difference. (Patient 2)                    |
|                               | Low feasibility  |  |
|                               | Lack of time for SDM because of cancer treatment constraints                     | I was told to make a decision within at least a few days. I don't think I even had a week.  (Patient 5, received a gynecological consultation on the day diagnosed with a cancer)  |
|                               | Lack of interdisciplinary collaboration  |  |
|                               | • Insufficient interdisciplinary communication regarding cancer treatment and FP | We do not explain it (decline in fertility) explicitlyAs<br>their (oncologist) plan isn't fully written there, I can't<br>know for sure. (Healthcare provider 3, fertility specialist)   |
|                               | Transferring responsibility to another healthcare providers                      | (In the oncology department) As they are busy, it feels like they're suggesting to just go and listen to the explanation first, sort of casually? (Healthcare provider 3, fertility specialist)  |
| Individual                    | Lack of awareness towards FP   |  |
| professional 1. Oncology team | Misconception that it is unnecessary outside cancer treatment                    | It seems like they're solely focused on treating lymphoma, and when it comes to asking (about fertility preservation), It's like they don't find it very important, just unnecessary. So, I just left it at that. I found it difficult to continue the conversation, so I couldn't bring it up further. (Patient 2)        |
|                               | Prejudgment on the need of FP, excluding<br>the patient                          | Doctors sometimes refrain from discussing such matters. It could be because the condition is severe, or perhaps there are biases on the doctor's part if there's a child involved. Moreover, some doctors might think it won't have much impact in cases where the disease is in its early stages. (Healthcare provider 2) |
|                               | Referring to the fertility clinic without explanation                            | They just suggested going to a nearby obstetrics and gynecology clinic if I was worried about (fertility). (Patient 2)  They don't really speak much, saying, 'just go to an obstetrics and gynecology clinic.' (Patient 11)   |
| 2. Fertility team             | Lack of awareness  |  |
|                               | Limited opportunity for SDM  | I went to the obstetrics and gynecology clinic for counseling, and they just assumed I was ready to proceed almost immediately. I thought they would at least suggest that I think about my decision, but as soon as I got there, they started scheduling procedure dates and everything. (Patient 1)                      |
|                               | Passive attitude   |  |
|                               | Without considering the patient's voice  | The obstetrics and gynecology professor mentioned that receiving cancer treatment may worsen ovarian function and decrease fertility. However, as the treatment is urgent at the moment, they advised against it. The professor said it doesn't seem to be the most important concern. (Patient 4)                         |
|                               |  | (Continues)  |

TABLE 1 | (Continued)

| Level               | Category and code   | Example quote  |
|---------------------|---|--|
|                     | Lack of explanations about various options                              | The hospital staff never explained anything about embryos to me, knowing I'm unmarried. (Patient 15, unmarried) They only talked about Zoladex. There was no mention at all about freezing embryos or anything like that. (Patient 8)  |
|                     | • Inadequate verification of patient comprehension of available methods | I only knew about egg freezing, so I said I would freeze<br>my eggs. There was no separate discussion about embryo<br>freezing; It seems like they just went along with it when<br>I said I would freeze my eggs (Patient 3, married)  |
| Patient with cancer | Lack of basic understanding about fertility decline and preservation    | At that time, I didn't know anything about breast cancer, so I had this vague idea that after treatment, I could just get pregnant. (Patient 10)   |
|                     | Difficulty in communication about FP                                    |  |
|                     | Not being prepared to ask some questions<br>about FP                    | 'What are you going to do? What do you choose?' It was kind of like that, so it didn't really come into my mind. You know, something to ask usually comes out when you are curious about something or understand something. (Patient 11)   |
|                     | Lack of opportunity for active discussion                               | They seemed very busy, so I couldn't ask many questions. They just said, 'Let's try the treatment together' and left. It felt like asking questions might be a bit bothersome. (Patient 10)  |
|                     | Passive attitude towards FP SDM   |  |
|                     | Dependence on doctor's judgment amid<br>insufficient information        | When I moved to the hospital in Seoul, they just said I needed to start cancer treatment quickly.  I assumed the priority that way, because they didn't mention that to me at all, So, I just received treatment like that. I thought the professor would take care of it well, so I trusted them (Patient 10)           |
|                     | Concerns that FP might delay or interfere with cancer treatment         | I started worrying that if the cancer treatment was delayed while I was looking into the options of egg freezing, my cancer might worsen. (Patient 10)   |
|                     | Psychological burden of decision-making                                 |  |
|                     | Difficulties making other decisions<br>because patients have cancer     | Just the reality of having cancer itself was so shocking, so that might have been why. Thus, getting treatment and starting chemotherapy right away were also completely new to me. It was already difficult because everything was new, but hearing that I needed to freeze my eggs added to the confusion. (Patient 5) |
| Social context      | Partner: Misalignment with the patient's decision                       | My boyfriend just said that treatment comes first, so<br>he hoped I wouldn't worry about having children and<br>would prioritize taking care of my body. That's how he<br>approached it. (Patient 15, decided on fertility preservation)   |
|                     | Mother: Misalignment with the patient's decision                        | Parents tend to prioritize their children without considering the distant future 'Let's focus on saving the daughter right now. Let's not waste time'. They believe things like freezing eggs are unnecessary. It's all just a marketing tactic. Some are quite upset about it. (Healthcare provider 6)                  |

**TABLE 1** | (Continued)

| Level                          | Category and code   | Example quote   |
|--------------------------------|---|---|
|                                | Online cancer community: Verifies biased choice and outcome | Many people experience a relapse after becoming pregnant. If you search on blogs, you'll find stories of people who relapsed while preparing for pregnancy, but at some point, there are no more posts. I believe they passed away. (Patient 4)   |
| Organizational context         | Frequent hospital changes                                   | As I went to a university hospital in a rural area, people around me kept suggesting that I should go to Seoul. That's why I ended up transferring to hospitals. (Patient 13)   |
|                                | An institution without a fertility clinic                   | Even universities like O University Hospital, don't cover fertility preservation, so patients come to us for consultation, and sometimes for testing as well. Subsequently, they return to their original hospital for treatment. (Healthcare provider 3)                                     |
|                                | Institutional mission where FP is not feasible              | At Catholic Foundation hospitals, they typically don't conduct procedures like in vitro fertilization, so banking itself becomes impossible. (Healthcare provider 3)  |
|                                | Short consultation time                                     | The consultation time is short. It's usually about 1 or 2 min, and if everything seems fine, they just tell you to go. That's how it is. (Patient 2)  Doctors at university hospitals are often so busy, so I think I had this subconscious feeling that I shouldn't bother them. (Patient 1) |
|                                | Deficiency in providing educational resources to patients   | It would have been nice if they had at least written it down or something for me to read. (Patient 10)  |
| Economic and political context | The high cost of FP   | I was also intimidated by the thought that it would cost a lot. I'm already worried about the money for the surgery, and I don't even know how much the treatment will cost. So, if it ends up costing a lot here, too, I was concerned about that as well. (Patient 10)                      |
|                                | No compensation for FP counseling                           | Due to the busy nature of the outpatient department, it is not feasible to explain everything. FP counseling is not compensated, so only healthcare providers who are interested in providing this counseling offer it, while those who are not interested do not. (Healthcare provider 2)    |
|                                | No policy support for FP in patients with cancer            | Talking about the birth rate and all that, it's a significant societal issue. However, couples going through IVF get support, while those who truly need it don't receive any support. I felt it was really unfair. (Patient 4)   |
|                                | Embryo cryopreservation limited to married                  | The probability of successful embryo freezing is higher<br>than that of egg freezing. However, when I heard that it's<br>only possible for married couples, I suggested we just go<br>registering the marriage, so we went together. (Patient 11)   |

another hindering factor, as patients relied predominantly on doctors' judgments with emerging concerns that engaging in FP SDM might delay or disrupt cancer treatment. Difficulties in making other decisions because patients have cancer were also identified as detailed codes for the psychological burden of decision making.

Conversely, patients demonstrated facilitators that enabled SDM, including sufficient knowledge about FP, communication skills, strong motivation and determination, and built trust in providers through respect and clear communication. They actively engaged in the process by researching FP options to acquire knowledge and prepare questions for their healthcare providers, even using tools such as notepads to aid discussions. For patients who had pre-existing pregnancy plans before cancer diagnosis, strong motivation and determination were particularly evident. Moreover, establishing trust with healthcare providers facilitated smoother implementation of SDM.

**TABLE 2** | Facilitators influencing implementation of SDM in fertility preservation.

| Level                                  | Category and code   | Example quote   |
|--|---|---|
| Innovation                             | Sufficient accessibility  |   |
|  | Patients selecting an institution/doctor that SDM is accessible | While considering transferring to a hospital, I chose O Hospital because they have multidisciplinary departments. As I had a lot of concerns about both breast cancer and pregnancy, I thought it would be great if they could address all of those aspects together. (Patient 15)  |
|  | Enhancing accessibility via<br>digital technology               | We usually have explanation videos called 'O Chart'. These videos explain why it's necessary. We also have an infertility KakaoTalk channel, so if they contact us via the KakaoTalk app, we reply to help guide them on when to come back for outpatient appointments. (Healthcare provider 3).  |
|  | Sufficient feasibility  |   |
|  | Respect for the patient's decision                              | Our job is to inform patients about it, and if the patient wishes in advance, to prepare for it. As our goal is not to make them fertile, it's a personal choice. (Healthcare provider 2, Breast Surgery)   |
|  | Alleviating the psychological<br>burden on patients             | They mostly come shortly after diagnosis. 'I don't understand why I need to do this, just to receive the treatment'. They may have various thoughts at home. I've seen cases where they somewhat give up. We must help them with emotional support. (Healthcare provider 6, Infertility Specialist Nurse)                               |
|  | • Inter-professional collaboration                              | We provide the professor with some prior information about the patients before they come in, so they can tailor the counseling accordingly. This allows the professor to prepare emotionally as well. (Healthcare provider 6, Infertility Specialist Nurse)   |
| Continuous quality improvement efforts |   | We are currently conducting patient satisfaction surveys. Through these surveys, we aim to understand whether patients regret their choices or not, which will help us gauge their satisfaction levels. (Healthcare provider 2)   |
| Individual professional                | Positive attitude   |   |
| 1. Oncology team                       | Asking about patient values<br>and preferences                  | The professor asked us about having a baby. So when our couple expressed a desire for a baby, the professor suggested that before starting cancer treatment, we should go to O Hospital, freeze embryos, and then proceed with the cancer treatment (Patient 7)   |
|  | Transparent and clear communication                             | The hospital informed me that the chemotherapy I'm receiving doesn't pose a significant risk of inducing menopause. It's less than 5%. This actually helped me in making decisions. (Patient 5)   |
|  | Empathetic support and proactive referrals                      | 'You are young. As I have lived longer than you, I appreciate the joy children bring to life. It is your choice but breast cancer is treatable'. Further, in my case, it's triple positive, so they said that there are many treatment options available, and I can still conceive. They reassured me not to be too afraid. (Patient 7) |
| 2. Fertility team                      | Sufficient awareness  |   |
|  | Giving patients an opportunity to deliberate                    | The professor explained everything about the process.<br>When preparing for embryo freezing, the professor said it<br>was the last chance to cancel if I wanted to. (Patient 14)  |

TABLE 2 | (Continued)

| Level                  | Category and code   | Example quote  |
|------------------------|---|--|
| Patient with cancer    | Sufficient knowledge about FP   | The doctor said that because I'm young, I need to undergo cancer treatment. From that point onwards, I decided to think about it and did considerable research until my next outpatient appointment. I extensively searched for information about the side effects of cancer treatment and even came across discussions about egg freezing, so I asked about it at my next outpatient visit. (Patient 3) |
|                        | Sufficient communication skills   | If there's anything I am curious about, I write down a list of questions I want to ask before leaving. I write them down and just show them. The doctor explained things to me, like a workbook, so it was easy for me to understand. (Patient 6)  |
|                        | Strong motivation and determination   | I was at an older age when I wanted to have children, thinking I should get pregnant quickly. However, after being diagnosed while preparing with such determination, it had a greater impact on me. (Patient 12)  |
|                        | Built trust in providers through respect and clear communication                | They are always kind whenever I go to outpatient visits or undergo tests. Naturally, they are kind but speak more from the patient's perspective. They show a lot of consideration from the patient's perspective, explain things in an easy-to-understand manner, and because I trust them, everything they do seems quite good to me. (Patient 6)  |
|                        |   | As the doctor responds promptly and clearly to every question I ask, it makes me feel relieved. It's like I feel more secure? In that aspect, I didn't find it particularly difficult. (Patient 9)   |
| Social context         | Financial stability through family support                                      | When I was receiving treatment, my mom paid for everything using her credit card. I just did it because my mom wanted me to do it comfortably. (Patient 15)  |
|                        | Building an active social support network and facilitating information exchange | Before going, I searched a lot on blogs, and many people seemed to be doing it. I thought that young people have to do it, so I also thought I had to do it. (Patient 15)  |
|                        |   | In an open chat room, there were people undergoing treatment as well as those who have completed it, and when you hear their stories, some say, 'You don't necessarily have to preserve your fertility, but if you don't want to regret it later, consider doing it like an insurance.' (Patient 11)   |
|                        | Social shift towards proactive FP among unmarried women                         | These days, even women in their late twenties or thirties who are not ill voluntarily opt for egg freezing, thinking about having children later. Hearing such stories can be somewhat comforting. (Patient 3)   |
| Organizational context | Multidisciplinary care (oncology, surgery, fertility team, etc.)                | The professors from the departments of Breast Surgery, Hematology, Oncology, Obstetrics and Gynecology, and Plastic Surgery all came in together for my consultation, from the initial diagnosis, so they could quickly help me schedule treatment appointments. From there, I also heard from the Obstetrics and Gynecology professor. (Patient 4)  |
|                        | Specialized care for reproductive cancer patients                               | There are centers prioritizing young cancer patients where<br>they fast-track the testing process. Owing to my young<br>age, they immediately referred me to the Obstetrics and<br>Gynecology department for further evaluation. (Patient 11)  |

TABLE 2 | (Continued)

| Level                          | Category and code  | Example quote   |
|--------------------------------|--|---|
|                                | Structured referral<br>to fertility clinic                               | They recommended that I go to the fertility center for counseling because I needed cancer treatment. Even though we didn't specifically request it, they immediately connected me, showing that the system is well-organized. (Patient 5)                           |
|                                |  | That could be part of the system, too. For fertility preservation patients, they immediately schedule outpatient appointments. (Healthcare provider 4)  |
|                                | Support system with care coordinator nurse specialized in fertility care | I met with the professor at the infertility center, and there was also a specialized nurse there, right? She explained in more detail how the procedure would proceed, the process of the injections, and other details more thoroughly. (Patient 13)               |
|                                |  | The importance and differences between egg freezing and embryo freezing were explained by the doctor.  Subsequently, in a separate consultation room, the nurse provided details on how the injections are administered and how to manage medications. (Patient 11) |
| Economic and political context | Policy support is provided for infertility cases (married)               | I realized that our country provides considerable support<br>for infertility. In our city, just to collect fresh embryos, they<br>provide a subsidy of 2 million won. Thus, as I mentioned<br>earlier, there was no financial burden. (Patient 7)                   |

Abbreviations: FP, fertility preservation; SDM, shared decision-making.

#### 3.3.4 | Social Context

At the social context, barriers to FP SDM were observed among significant others. Discordant opinions from partners (spouses or boyfriends) or mothers (especially in unmarried cases) hindered SDM implementation when they did not align with the patient's decision. In some instances, they opposed considering FP, perceiving it as a barrier that disrupted treatment focus. Furthermore, the biased choices and outcomes observed within the online cancer community impeded balanced SDM. For instance, patients became more apprehensive about the risks of pregnancy and the possibility of recurrence upon encountering tragic cases in which individuals in online cancer communities attempted pregnancy and ended up dying.

Conversely, financial stability through family support has alleviated the burden on patients regarding FP SDM, while simultaneously building an active social support network and facilitating information exchange has further bolstered decision-making abilities and instilled confidence. Additionally, recent years have witnessed a notable positive shift in the awareness of oocyte cryopreservation among unmarried women in Korean society, which has been disseminated through various media channels. This societal transformation also has had a positive impact on FP SDM.

## 3.3.5 | Organizational Context

In the organizational context, several barriers were identified, including frequent hospital transfers, an institution without a fertility clinic, an institutional mission where FP is not feasible,

short consultation times, and a deficiency in providing educational resources to patients. These factors collectively hindered SDM implementation. Specifically, frequent hospital transfers following a cancer diagnosis disrupted the continuity of care and impeded SDM processes. In an institution without a fertility clinic, patients faced difficulties in accessing FP, as they needed to utilize fertility clinics at other facilities. Moreover, institutional missions for which FP is not feasible further complicated SDM efforts, especially for patients requiring FP discussions. Additionally, patients diagnosed at tertiary hospitals in the capital faced challenges due to short consultation times, which limited the depth of SDM discussions. Finally, a deficiency in the provision of educational resources to patients has emerged as a significant barrier.

SDM implementation was more likely to occur in organizations equipped with facilitators such as multidisciplinary care, specialized care for reproductive patients with cancer, structured referral to fertility clinics, and a support system including care coordinator nurses specialized in fertility care. Further, when patients were provided with sufficient consultation time, they could express themselves adequately, enhancing their SDM. Moreover, a support system with care coordinator nurses specializing in fertility care, who provide practical education and address patient enquiries, played a crucial role in supporting patients' SDM.

#### 3.3.6 | Economic and Political Context

In an economic context, the high cost of FP posed a significant burden on patients, hindering the execution of SDM. In the political context, while married women diagnosed with infertility could receive partial financial support for FP, financial assistance for FP targeted at patients with cancer was lacking, leading to substantial inequality among patients. However, some married patients with cancer were included in the infertility support program and received financial assistance. Finally, in Korea, embryo cryopreservation is only permitted for married women. Additionally, there is no compensation for FP counseling, which results in a reduced willingness among healthcare providers to offer these services.

## 4 | Discussion

This study explored barriers and facilitators in implementing FP SDM among patients with cancer using a multilevel implementation framework and proposed strategies for its successful implementation.

First, at the innovation level, accessibility emerges as a critical factor. This study revealed instances where patients were not informed about FP by their healthcare providers prior to commencing cancer treatment, leading to missed opportunities for SDM. It underscores the importance of providing patients undergoing gonadotoxic treatments with pertinent information (Mehedintu et al. 2021). Ensuring consistency in SDM implementation across institutions and physicians necessitates an effective information delivery system, informing patients about FP (Alesi et al. 2023). Mandating documentation of fertility-related discussions, leveraging EMR alert systems for fertility-impacting treatments, and encouraging providers to offer additional FP options can streamline the process, ultimately easing the burden on oncology teams (Bhave et al. 2019; Pathak et al. 2023).

At the innovation level, another important factor emerged as feasibility. Contrary to patients with chronic illnesses, who have sufficient time for SDM (Aoki 2020; Mathijssen et al. 2020), patients with cancer must make urgent decisions because of the imperative nature of cancer treatment (Aoki 2020; Mathijssen et al. 2020). This urgency is compounded by a lack of trust in health care providers and insufficient time to prepare adequately for SDM (Hoffman et al. 2021). This parallels findings from previous research (Huang et al. 2022), suggesting that recognizing disparities in perceptions of timing and the amount of information needed for decision-making between patients and providers and proposing collaborative discussions and personalized educational materials could be beneficial (Speller et al. 2019). To enhance the feasibility of FP SDM and alleviate patients' decision-related distress, specialized care coordinator nurses in onco-fertility care can offer psychological support and decision coaching.

Finally, at the innovation level, interdisciplinary collaboration emerged as crucial, as evidenced by insufficient collaboration among participants limiting patient access to necessary information. This issue also raised concerns about oncology teams delegating SDM responsibilities to the fertility team, mirroring trends in pediatric and adolescent cancer patient studies (Hoogenboom et al. 2018). Moreover, role ambiguity and role conflict among healthcare providers have been reported in several studies (Crespi et al. 2021; Speller et al. 2019), in which

oncology providers felt that providing FP resources was not their role and were unclear about who should take responsibility for it. To address these challenges, implementing effective strategies like multidisciplinary clinics is essential (Dolmans et al. 2019), alongside further education and clear guidelines to bolster healthcare providers' engagement in FP SDM, as recommended by Keim-Malpass et al. (2018).

Second, at the individual professional level in the oncology team, lack of awareness towards FP emerged as a barrier, whereas a positive attitude was identified as a facilitator. The lack of awareness towards FP may result from the role ambiguity described above or from a lack of knowledge and confidence (Salsman et al. 2021; Sehring et al., 2021). In addition to FP content education and role clarification, further training on SDM processes and essential skills including communication can address these issues (Brown et al. 2022; Crespi et al. 2021; Speller et al. 2019; Xiao et al. 2024). Within the fertility team, lack of awareness and a passive attitude have been identified as barriers to implementing SDM. Unlike previous studies primarily focusing on oncologists, this research uniquely explored SDM barriers and facilitators from the patients' perspective (Keim-Malpass et al. 2018; Salsman et al. 2021). This study uniquely identified barriers to and facilitators of SDM implementation within the fertility team because it approached the issue from the perspective of patients. Patients highlighted instances where fertility specialists assumed decisions regarding FP, bypassing SDM and proceeding directly with procedures. However, it has been demonstrated that providing opportunities for patient involvement is beneficial when there is sufficient awareness of SDM. Therefore, it is deemed essential for the fertility team to undertake education on SDM implementation.

Third, at the patient level, similar outcomes have been reported as barriers and facilitators in the SDM context for patients with cancer, such as basic understanding, communication, attitude, and informed decision-making (Joseph-Williams et al. 2014; Roodbeen et al. 2020; Waddell et al. 2021). The findings from quantitative research on SDM among patients with cancer highlight the significance of health literacy (Nahata et al. 2023), suggesting that healthcare providers should prioritize it to facilitate informed decision-making regarding FP. Particularly in the context of FP SDM, patients expressed concerns about choosing FP because of fear of its negative impact on treatment, which hindered SDM performance. Both oncology and fertility healthcare providers must understand their patients' complex challenges and develop compassionate yet professional communication skills to convey essential information effectively. They should allocate sufficient time for decision-making and provide emotional support, prioritizing patient-centered care, especially for patients facing the daunting task of deciding amidst a cancer diagnosis.

Fourth, in the social context, conflicts between partners or parents regarding decisions on FP were identified as barriers, whereas alignment of opinions was found to be a facilitator. The perspectives of parents, who often cover the costs of FP, and partners, who contribute sperm for embryo freezing, notably influence the patients' SDM. However, partners and parents commonly prioritize the patient's immediate treatment over future fertility discussions, potentially impeding SDM

implementation. In Asian countries, family culture significantly influences health-related decision-making, particularly in FPrelated choices for female patients with cancer, as highlighted in several studies (Huang et al. 2022; Xiao et al. 2024). Considering the diverse cultural backgrounds and values within each family, these interventions can help address barriers and promote SDM implementation (Mathur et al. 2021). Additionally, factors related to online cancer communities (e.g., blogs and social network services) were identified in the social context. While these online communities can be beneficial by fostering a sense of belonging and personal development, facilitating communication with other patients with cancer and survivors, and obtaining personalized information, biased choices and outcome verification can hinder SDM. Therefore, further education on digital literacy and safe online activities can contribute to the formation of healthier online communities (Gentile et al. 2018). Finally, the media's FP description for unmarried women in Korea in recent years has created a positive impact on the decision-making of patients with cancer regarding FP (Cho and Kim 2017). Further studies should be conducted to identify how to effectively use media materials to increase public awareness and positive impressions of FP among unmarried women.

In the organizational context, barriers to implementing SDM include frequent post-diagnosis hospital transfers by patients with cancer, multiple visits if FP services are not available within one institution, and insufficient consultation times. In particular, when oncology and fertility teams are not co-located within the same institution, there could be a greater risk of restricted information exchange and a lack of coordinated care. Organizational efforts to build and strengthen policies for inter-hospital collaboration to establish standardized, streamlined, and secure information exchange and referral systems could address these barriers (Gentile et al. 2018). Based on our findings showing the advantages of well-structured multidisciplinary care or specialized care teams for patients with cancer, organizations can build strategies to implement such systems in their current settings. Specifically, care coordinator nurses with ample knowledge and skills in fertility care can play a crucial role in improving health outcomes and increasing patient satisfaction (Brown et al. 2022; Dorfman et al. 2021; Wright et al. 2022). While these nurses can provide opportunities for communication, answer patient queries, offer psychological support, and serve as patient-centered decision coaches in the decision-making process, they can also work as coordinators of the overall cancer care system for patients and their families, including in-depth assessment, scheduling, empowering their engagement in SDM, and providing important information (Armato et al. 2020; McMullen 2013; Sehring et al. 2021). Currently, nurses occupy a beneficial position in enhancing FP care for patients with cancer; however, their involvement remains limited (Crespi et al. 2021; Van den Berg et al. 2020). Consequently, interventions are needed to strengthen their role by reinforcing institutional and policy support for nurses.

In Economic and Political contexts, many participants have reported the high cost of FP as one of the critical barriers to SDM implementation. Currently, in South Korea, reimbursement for fertility procedures is limited to patients with infertility, leaving patients with cancer feeling marginalized because of the lack of policies supporting them financially (Park and Kang 2022).

While some married patients with cancer may qualify for government support by obtaining an infertility diagnosis, this option is highly restricted. Given the unique circumstances of FP for patients with cancer, policies that support the cost of FP specifically for them are needed urgently (Walter et al. 2017). Furthermore, this study noted the lack of fee-for-service for FP counseling. This underscores the importance of various policy supports, such as providing financial assistance to patients and offering incentives to both providers and organizations, in promoting the implementation of FP SDM.

#### 4.1 | Limitations

This study presents a novel approach to exploring the barriers and facilitators of implementing SDM in fertility care for patients with cancer by applying a multi-level IS framework. Such approaches have helped to understand complex factors from a more systematic perspective. Despite these efforts, this study has some limitations. First, our participants were predominantly patients with breast cancer, particularly unmarried patients, even though we did not explicitly target a specific diagnosis. This discrepancy in our participants could result from the high incidence rates of breast cancer in Korean women and should be considered when interpreting the results, as this population may have unique experiences that differ from other diagnoses. Additionally, the presence of fertility clinics within some cancer hospitals may reflect characteristics specific to the Korean healthcare system, necessitating careful consideration when interpreting the results. Furthermore, we could also reach only a few healthcare providers, including one oncologist, due to recruitment challenges, which limited the scope of our exploration. Although our interview guidelines included multiple questions about SDM, the participants' responses were relatively superficial. Our future studies will apply more innovative and creative methods to obtain profound and lived experiences of FP SDM in patients with cancer. Furthermore, we only included individual patients and a narrow scope of healthcare providers in oncology and fertility care teams, while FP SDM could include a broader scope of members, including families, genetic counselors, bedside nurses, social network communities, and other community members who could have an indirect influence on decision-making. Future studies should consider expanding the target population to obtain a more comprehensive understanding of FP SDM implementation in patients with cancer.

## 5 | Conclusion

This study explored barriers and facilitators in implementing FP SDM among female patients with cancer using a multilevel implementation framework and proposed strategies for its successful implementation. In this study, at the individual level, patients expressed that knowledge, attitudes, and capabilities regarding FP SDM were associated with its implementation. Among healthcare providers, awareness and attitudes towards FP and SDM were crucial factors in implementing FP SDM. Interestingly, even among healthcare providers, oncologists and fertility specialists had different perspectives on FP SDM, which hindered interdisciplinary collaboration and the integration of FP SDM in clinical practice. At the system level, financial issues,

including patients' cost burden for FP and the lack of adequate compensation for healthcare providers participating in FP SDM, were identified as barriers. Therefore, various policy supports, such as enhancing social awareness about FP SDM, providing financial assistance to patients, and offering incentives to both providers and organizations, can promote its implementation. Furthermore, nurturing nurse specialists to coordinate FP SDM and developing decision aids can help address system-level challenges. Further research should aim to enhance FP SDM implementation based on these strategies, ultimately bridging the research-to-practice gap and improving patient outcomes.

#### 6 | Clinical Resources

- American Society of Clinical Oncology (ASCO)—Fertility Preservation Guidelines: https://www.asco.org/guidelines/ GUIDELINEASCO9661
- National Comprehensive Cancer Network (NCCN)— Adolescent and Young Adult (AYA) Oncology Guidelines: https://www.nccn.org/guidelines/guidelines-detail?categ ory=4&id=1412
- Oncofertility Consortium-Patient and Provider Resources: https://oncofertility.msu.edu/
- American Society for Reproductive Medicine (ASRM)
   Fertility Preservation for Patients with Cancer: https://www.asrm.org/practice-guidance/coding/coding-summaries/fertility-preservation

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The authors have nothing to report.

#### **Ethics Statement**

The institutional research board of Chung-Ang University (IRB No.: 1041078-202203-HR-101) approved the study protocol.

#### **Conflicts of Interest**

The authors declare no conflicts of interest.

#### **Data Availability Statement**

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

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#### **Supporting Information**

Additional supporting information can be found online in the Supporting Information section.