

# Factors Influencing Communication Quality for Successful Fertility Preservation Counselling for Adolescent and Young Adult Cancer Patients and Their Care Givers in Korea

**Yoo Sub Shin**

Yonsei University College of Medicine

**Mi Na Park**

Yonsei Cancer Center

**Seung Min Hahn**

Yonsei University College of Medicine

**Seung Yeon Kwon**

Yonsei University College of Medicine

**Won Kee Ahn**

Yonsei University College of Medicine

**Chuhl Joo Lyu**

Yonsei University College of Medicine

**Jung Woo Han** (✉ [jwhan@yuhs.ac](mailto:jwhan@yuhs.ac))

Yonsei University College of Medicine <https://orcid.org/0000-0001-8936-1205>

---

## Research Article

**Keywords:** fertility preservation, adolescent and young adults, discussion, communication, oncofertility

**Posted Date:** February 1st, 2022

**DOI:** <https://doi.org/10.21203/rs.3.rs-1216286/v1>

**License:**   This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

---

# Abstract

## Purpose

Fertility preservation (FP) discussion is a crucial step for adolescent and young adult (AYA) cancer patients; however, it is relatively new to Asian countries. This study highlights the quality of communication during FP discussions in Korea.

## Methods

Participants were AYA patients (n = 34) and their guardians (n = 34). We described clinical pathways for FP and surveyed details on the discussion characteristics and satisfaction scales during the FP discussions in Yonsei Cancer Center, Seoul, Korea. Quality of FP discussions and the degree of satisfaction with the discussions were measured on a scale of 1–7.

## Results

Of the participants, two guardians did not answer the survey. All respondents reported high overall satisfaction; however, several factors were related to low satisfaction or information quality. Regarding the type of counselors, both respondent groups reported high overall satisfaction when their counselors were physicians rather than other types of care providers. Regarding information quality, guardians who were provided with both verbal and non-verbal communication tools (pamphlets, internet resources, or others) were more satisfied with the information quality than those who were provided with only verbal communication tools. Regarding the number of discussion sessions, more than one discussion session indicated improved understanding of the FP concept, higher communication, and information quality.

## Conclusion

To improve the FP process for AYA cancer patients, we need to adjust the type of counselors, number of discussion sessions, and types of information. This will be the cornerstone of effective FP communications in Korea.

## Introduction

The preservation of fertility is an issue of high priority among adolescent and young adult patients with cancer or cancer survivors for their future quality of life[1]. Health care providers should discuss fertility preservation (FP) with patients and refer them to reproductive specialists[2]. Various strategies such as sperm cryopreservation or hormonal gonadal protection for men and embryo or oocyte cryopreservation for women are commonly employed. Details on the role and limitations of these preservation options should be discussed during FP discussion sessions[2].

To effectively and successfully provide quality oncofertility, multifaceted approaches to connect cultures, communities, and countries as well as a multidisciplinary team comprised of oncologists, reproductive specialists, patients, families, and researchers are needed[2, 3]. For better counseling and decision-making processes, various modalities have been developed and are currently incorporated during discussions [4].

Despite consensus regarding the importance of oncofertility, there are many barriers and challenges to FP for patients, such as initiating the communication, training professionals, preparing and providing education materials, or psychosocial and ethical issues[5]. The first step of FP for patients with cancer is raising awareness among clinicians and obtaining appropriate referrals. However, many institutions lack a proper guidance system that provides appropriate communication on oncofertility[5–7]. Age related issues, considerations, and relevant approaches should be emphasized during the conversation, especially for adolescent patients[6].

Clinical practice and research on FP have been undertaken in Asian countries. In Korea, the Korean Society for Fertility Preservation (KSFP) was established in 2013 to facilitate multidisciplinary discussions and network. However, Korea is facing many obstacles such as referrals, financial burden, insurance coverage etc.[8]. Multiple reasons are associated with these problems. Communication barriers on FP are one of the obstacles that currently restrict quality fertility care. There has been a lack of awareness and little recognition of the oncofertility field even among health care providers[1]. The insufficiency of quality communication between health care providers and patients inhibits the oncofertility process[5]. Health care professionals should understand the needs of adolescent and young adult (AYA) patients regarding reproductive health issues in an age-appropriate manner[1, 9]. The lack of communication partly stems from deficient knowledge of adverse effects of gonadotoxic treatments, improper timing of FP discussions, psychosocial impact of disrespectful discussions, or low quality of information[10–12]. As the time frame from diagnosis to the start of cancer treatment is short, it is necessary to maximize the quality and efficiency of communication for a successful oncofertility process and cancer treatment for specific patients. This study aims to identify limiting factors regarding FP discussions in Korea, to improve their quality. To do this, we performed a survey study among AYA cancer patients and their corresponding guardians who have attended discussions on FP.

## **Materials And Methods**

### **Study population**

Participants were AYA cancer patients (and their guardians) aged 10–25 years who attended FP discussion at the department of pediatric hemato-oncology of Yonsei Cancer Center, Yonsei University Health System (YUHS) in Seoul, Korea from December 2019–November 2020. The survey took place in both in- and out-patient settings in two separate rooms. Patients and their guardians independently answered the questionnaire accompanied by researchers. Demographic and medical information was retrieved from the electronic medical records system at our institution. The study was approved by the

institutional review board at Severance Hospital, YUHS (IRB no. 4-2019-0868). All participants provided informed consents of this study.

## **Measures**

The survey was categorized into three sections: background information and demographics, characteristics of FP discussion, and quality of FP discussions and communications. Subsequently, we assessed whether demographics or characteristics of the discussion affected respondents' evaluation of FP discussion sessions. The questions were constructed based on guidelines and previous reports on facilitation of appropriate communication and improved quality of FP discussions[2, 5, 13].

## **Background information**

The questions identified potential demographic factors that may influence respondents' experience of FP discussions. Questions pertained to the guardian's relationship with the patient, previous knowledge of FP, and the main decision maker regarding FP.

## **Characteristics of FP discussion sessions**

The survey evaluated the structure of the discussion. Characteristics assessed were the total number of discussions held, duration of each discussion, the identity of the information provider, the provider's gender, and the timing of the discussion.

## **Satisfaction scores and quality of FP discussion sessions**

The overall satisfaction and subcategories of satisfaction were measured on a scale of 1–7, where 7 indicates the highest satisfaction. The subcategory includes satisfaction associated with the quality of information, the quality of communication, and the patient or caregiver expectation on the future quality of life through the FP process.

## **Statistical analysis**

A survey of 34 pairs of patients and their guardians was completed and the results analyzed. Descriptive analysis evaluated the demographics of the patients and their guardians. Data are presented as the median with interquartile range (IQR), percentage or mean  $\pm$  standard deviation. Wilcoxon rank sum test was used for non-parametric variables (characteristics of FP discussion and demographics) to evaluate for differences in participants' evaluation of FP discussions. All statistical analysis was performed using R Statistical Software version 3.6.3 (Foundation for Statistical Computing, Vienna, Austria).

## **Results**

### **Demographics**

A total of 34 pairs of patients and their guardians were contacted during in-hospital or out-patient clinic visits. Of them, 34 patients and 32 corresponding guardians completed the survey (two guardians did not

respond to the survey; Table 1).

Table 1  
Patient and Guardians Demographics

| Characteristics                           |                           | Categories     | n (%)   | Mean±SD   |
|---|---------------------------|----------------|---------|-----------|
| Guardians' Characteristics                | Relationship with patient | Father         | 4 (13)  |           |
|   |                           | Mother         | 25 (81) |           |
|   |                           | Both           | 2 (6)   |           |
|   | Previous knowledge of FP  | knows well     | 4 (13)  |           |
|   |                           | heard of       | 8 (25)  |           |
|   |                           | never heard of | 20 (63) |           |
| Patients' Characteristics                 | Gender                    | Male           | 18 (53) |           |
|   |                           | Female         | 16 (47) |           |
|   | Age                       | ≤15            | 19 (56) |           |
|   |                           | >15            | 15 (44) | 15.3±2.97 |
|   | Diagnosis Type            | Leukemia       | 11 (32) |           |
|   |                           | Sarcoma        | 8 (24)  |           |
|   |                           | Brain tumor    | 4 (12)  |           |
|   |                           | Lymphoma       | 4 (12)  |           |
|   |                           | Others*        | 7 (21)  |           |
| Timing of FP Consultation Since Diagnosis | ≤10 days                  | 28 (82)        |         |           |

\*Others include pancreatic solid pseudopapillary tumor, mesothelioma, severe aplastic anemia, retinoblastoma, Wilms tumor, renal cell carcinoma, germ cell tumor

Acronyms and abbreviations: FP, fertility preservation

| Characteristics  | Categories                               | n (%)   | Mean±SD |
|--|--|---------|---------|
|  | >10 days                                 | 6 (18)  |         |
| FP Success   | Success                                  | 31 (91) |         |
|  | Failure                                  | 3 (9)   |         |
| Previous Knowledge of FP before the FP discussion  | knows well                               | 2 (6)   |         |
|  | heard of                                 | 8 (24)  |         |
|  | never heard of                           | 24 (71) |         |
| Main Decision Maker for FP   | Guardian                                 | 11 (37) |         |
|  | Patient                                  | 4 (13)  |         |
|  | Doctor or other health care professional | 15 (50) |         |
|  | Others                                   | 0 (0)   |         |
| *Others include pancreatic solid pseudopapillary tumor, mesothelioma, severe aplastic anemia, retinoblastoma, Wilms tumor, renal cell carcinoma, germ cell tumor |  |         |         |
| Acronyms and abbreviations: FP, fertility preservation   |  |         |         |

The mean age of patients was  $15.3 \pm 2.97$ , with half of the group (56%) under 15 years old. The most common type of cancer was leukemia (32%), followed by sarcoma (24%), brain tumor (12%), lymphoma (12%) and others. Prior to FP counseling, most respondents (guardian: 63%, patient: 71%) had never heard of the concept of FP. Twenty-eight patients (82%) attended the FP discussion within 10 days after the time of diagnosis. After the discussion sessions, all patients agreed to proceed with FP. Among them, 31 patients successfully completed the procedure, and three patients failed the sperm cryopreservation procedures.

### Fertility Preservation Discussion Characteristics: Responses from Patients

Out of 34 participant patients, 32 responded that they had attended at least one discussion session prior to FP (Table 2). Only one discussion session was conducted for 17 patients (53%), and more than one session was conducted for the others. The options of FP were discussed before the start of cancer treatment for 29 (86%) patients; however five patients attended discussions after the start of cancer

chemotherapy. Each discussion session was held for less than 10 minutes for 28 patients (87%). Only one patient (3%) attended a session that lasted between 20–30 minutes. There was no session with a duration of 30 minutes or longer.

Table 2  
Fertility preservation discussion characteristics (n=number of respondents)

|  | <b>Responder</b>     | <b>Category</b>         | <b>n (%)</b> |
|--|----------------------|-------------------------|--------------|
| Total number sessions of FP discussion | Patient (N=34)       | Once                    | 17 (53)      |
|  |                      | Twice                   | 8 (25)       |
|  |                      | Three Times             | 3 (9)        |
|  |                      | Four Times or More      | 4 (13)       |
|  |                      | None                    | 2 (6)        |
|  | Guardian (N=32)      | Once                    | 17 (53)      |
|  |                      | Twice                   | 7 (22)       |
|  |                      | Three Times             | 4 (13)       |
|  |                      | Four Times or More      | 4 (13)       |
|  |                      | None                    | 0 (0)        |
| Timing of FP consult                   | Patient (N=34)       | Right After Diagnosis   | 8 (24)       |
|  |                      | Before Cancer Treatment | 21 (62)      |
|  |                      | After Cancer Treatment  | 5 (15)       |
|  | Guardian (N=32)      | Right After Diagnosis   | 7 (22)       |
|  |                      | Before Cancer Treatment | 21 (66)      |
|  |                      | After Cancer Treatment  | 4 (12)       |
| Duration of each consult               | Patient (N=32, NA=2) | less than 10 min        | 28 (88)      |
|  |                      | 10~20 min               | 3 (9)        |

Acronyms and abbreviations: FP, fertility preservation

|   | Responder            | Category                     | n (%)   |
|---|----------------------|------------------------------|---------|
|   |                      | 20~30 min                    | 1 (3)   |
|   |                      | more than 30 min             | 0 (0)   |
|   | Guardian (N=32)      | less than 10 min             | 26 (81) |
|   |                      | 10~20 min                    | 4 (13)  |
|   |                      | 20~30 min                    | 1 (3)   |
|   |                      | more than 30 min             | 1 (3)   |
| When did the patient first understand the concept of FP | Guardian (N=32)      | After first counsel          | 15 (47) |
|   |                      | In later counseling sessions | 3 (9)   |
|   |                      | After guardian's explanation | 12 (38) |
|   |                      | Does not understand still    | 2 (6)   |
|   | Patient (N=32, NA=2) | After first counsel          | 15 (47) |
|   |                      | In later counseling sessions | 3 (9)   |
|   |                      | After guardian's explanation | 8 (25)  |
|   |                      | Does not understand still    | 6 (19)  |
| Who was your main counselor                             | Patient (N=34)       | Pediatric Hemato-oncologist  | 3 (9)   |
|   |                      | Gynecologist                 | 19 (56) |
|   |                      | Resident                     | 2 (6)   |
|   |                      | Nurse                        | 1 (3)   |
|   |                      | Others                       | 9 (26)  |
|   | Guardian (N=32)      | Pediatric Hemato-oncologist  | 5 (16)  |
|   |                      | Gynecologist                 | 12 (38) |

Acronyms and abbreviations: FP, fertility preservation

|                                       | Responder            | Category                              | n (%)   |
|---------------------------------------|----------------------|---------------------------------------|---------|
|                                       |                      | Resident                              | 8 (24)  |
|                                       |                      | Nurse                                 | 5 (16)  |
|                                       |                      | Others                                | 2 (6)   |
| What was the Counselor's Gender       |                      | Same as Patient                       | 19 (59) |
|                                       |                      | Different from Patient                | 11 (34) |
|                                       |                      | Both Parents                          | 2 (6)   |
| Where did the Consultation take place | Patient (N=33, NA=1) | Outpatient ward                       | 2 (6)   |
|                                       |                      | Bedside in a multi-beds hospital room | 21 (64) |
|                                       |                      | Private Room                          | 1 (3)   |
|                                       |                      | Infertility Clinic                    | 6 (18)  |
|                                       |                      | Hospital Hallway                      | 0 (0)   |
|                                       |                      | Others                                | 3 (9)   |
|                                       | Guardian (N=32)      | Outpatient ward                       | 4 (13)  |
|                                       |                      | Bedside in a multi-beds hospital room | 14 (44) |
|                                       |                      | Private Room                          | 5 (16)  |
|                                       |                      | Infertility Clinic                    | 5 (16)  |
|                                       |                      | Hospital Hallway                      | 4 (13)  |
|                                       |                      | Others                                | 0 (0)   |
| How was the FP consultation delivered | Patient (N=33, NA=1) | Verbal only                           | 25 (76) |
|                                       |                      | Notes and Pictures                    | 3 (9)   |

Acronyms and abbreviations: FP, fertility preservation

| Responder  | Category           | n (%)   |
|--|--------------------|---------|
| Guardian<br>(N=32)                                     | Pamphlets          | 2 (6)   |
|  | Videos             | 0 (0)   |
|  | Internet sources   | 1 (3)   |
|  | Others             | 2 (6)   |
|  | Verbal only        | 28 (88) |
|  | Notes and Pictures | 2 (6)   |
|  | Pamphlets          | 1 (3)   |
|  | Videos             | 0 (0)   |
|  | Internet sources   | 1 (3)   |
|  | Others             | 0 (0)   |
| Acronyms and abbreviations: FP, fertility preservation |                    |         |

The main counselors at the discussion were either gynecologists (N = 19), others (N = 9), pediatric hematology-oncology specialists (N = 3), and residents in pediatrics (N = 2), or a nurse (N = 1). Patients who responded with “others” to this question, mostly referred to their own guardians as their main counselor. Nineteen (59%) counselors were of the same gender as the patients.

Twenty-one (64%) patients reported that the discussion was held at their bedside in a multi-beds hospital room, while only nine (27%) patients attended the discussion in a private setting (private room, infertility clinic, outpatient ward). A private setting indicates a place where there is no possibility of the discussion being overheard by others not involved in the oncofertility process.

Most discussions (N = 25, 76%) took place solely through verbal communication, without the use of memos, notes, information sheets, pamphlets, or internet resources.

Overall, less than half of the patients (N = 14, 47%) reported that they understood the concept of FP sufficiently to make proper decisions to proceed or not, after the first discussion session. Six (19%) patients reported they did not understand FP at all, even after the completion of all FP discussion sessions.

### **Fertility Preservation Discussion Characteristics: Responses from Guardians**

All 32 guardians reported that they attended FP discussions before deciding on FP. Twenty-seven guardians (87%) reported the patients went through the discussion before cancer treatment. Seventeen guardians (53%) reported the session was held only once.

Of the 32 guardians, 26 (81%) reported that discussions were held for less than 10 minutes. Only one guardian (3%) attended a discussion session lasting over 30 minutes.

The main counselors at the discussion for guardians were either gynecologists (N = 14), residents (N = 9), pediatric hematology-oncologists (N = 6), nurses (N = 5), or others (N = 3).

Fourteen (44%) guardians discussed FP at the patient's bedside, and fourteen (44%) guardians discussed the issue in a private setting. Four guardians (13%) attended the discussion at a hospital hallway. Most discussions were delivered solely through verbal communication (88%).

### **Satisfaction of Fertility Preservation Discussion**

All 10 questions averaged a score higher than 4, which means higher than average, indicating that patients and guardians were generally satisfied with the counseling process (Table 3).

Table 3  
Survey topics and responses by the respondents about of FP consult discussion sessions

| Survey topic  | Survey question   | Responder | Median | Q1-Q3     | Mean ± SD | <i>p</i> |
|---------------|---|-----------|--------|-----------|-----------|----------|
| Satisfaction  | 1. Overall Satisfaction with FP process   | Patient   | 5      | 4~6       | 5.06±1.43 | 0.95     |
|               |   | Guardian  | 5      | 4~6       | 5.03±1.49 |          |
|               | 2. Positive expectation on the future quality of life by the FP process   | Patient   | 5.5    | 5~7       | 5.50±1.36 | 0.38     |
|               |   | Guardian  | 6      | 5~7       | 5.69±1.58 |          |
|               | 3. Was the FP discussion helpful to make your final decision on FP process?                                     | Patient   | 6      | 5~7       | 5.65±1.28 | 0.42     |
|               |   | Guardian  | 6      | 5~7       | 5.75±1.57 |          |
| Information   | 4. Quality of information during FP discussion  | Patient   | 5.5    | 5~6       | 5.35±1.41 | 0.95     |
|               |   | Guardian  | 5      | 4.75~6.25 | 5.38±1.31 |          |
|               | 5. Sufficient quantity of information to make decision on FP process  | Patient   | 6      | 4~7       | 5.13±1.75 | 0.34     |
|               |   | Guardian  | 5      | 3~6       | 4.69±1.91 |          |
|               | 6. Were the contents easy to understand   | Patient   | 6      | 5~7       | 5.65±1.20 | 0.33     |
|               |   | Guardian  | 6      | 4~6.25    | 5.09±1.8  |          |
|               | 7. Need for suitable referrals to FP specialists prior to final decision on FP process despite of FP discussion | Patient   | 4      | 3~6       | 4.19±1.74 | 0.35     |
|               |   | Guardian  | 5      | 3~6       | 4.62±1.93 |          |
| Communication | 8. Overall quality of communication during FP discussion  | Patient   | 6      | 4.25~6    | 5.35±1.54 | 0.53     |

Acronyms and abbreviations: FP, fertility preservation

| Survey topic   | Survey question                                      | Responder | Median | Q1-Q3  | Mean ± SD | <i>p</i> |
|--|--|-----------|--------|--------|-----------|----------|
|  |  | Guardian  | 5      | 4~6    | 5.19±1.47 |          |
|  | 9. Was your privacy well protected?                  | Patient   | 6      | 5~7    | 5.84±1.16 | 0.63     |
|  |  | Guardian  | 6      | 5~6.25 | 5.69±1.23 |          |
|  | 10. Was the entire FP discussion respectful for you? | Patient   | 6      | 5~7    | 6.03±1.08 | 0.38     |
|  |  | Guardian  | 6      | 5.75~7 | 5.72±1.37 |          |
| Acronyms and abbreviations: FP, fertility preservation |  |           |        |        |           |          |

### Patients' responses

Patients were mostly satisfied with the discussion sessions. They reported highest satisfaction with the protection of the patients' privacy (Question 9, 5.84 ± 1.16) and a respectful attitude during the discussion process (Question 10, 6.03 ± 1.08). Low levels of satisfaction were found with additional available information provided (Question 5, 5.13 ± 1.75). They did not report other suitable referrals to professionals regarding FP issues rather than FP discussion (Question 7, 4.19 ± 1.74).

The overall satisfaction rate was higher among patients who were counseled by doctors (gynecologists, pediatric hema-oncologists, residents) than respondents who were counseled by nurses or other counselors (Fig. 1-A, *p* = 0.015).

### Guardians' Responses

Responses from guardians showed trends similar to patients' responses. Guardians were mostly satisfied with how the consult took place, represented in privacy and respectfulness; questions 9 and 10 (5.69 ± 1.23; 5.72 ± 1.37, respectively). The lowest scoring responses were identical with that of the patient's, represented in quantity of information and suitable referrals (Question 5, 4.69 ± 1.91). They did not report the need for other referrals despite of FP discussion (Question 7, 4.62 ± 1.93).

Guardians who were counseled by doctors showed higher overall satisfaction compared with guardians counseled by nurses or other counselors (Fig. 1-B, *p* = 0.01).

### Factors affecting respondent satisfaction

#### Communication Quality: Impact by the type of information providers

Patients counseled by doctors rather than other types of health care providers reported greater satisfaction with the quality of information delivered (Fig. 1-C, *p* = 0.001) and the quality of

communication (Fig. 1-D,  $p = 0.001$ ). However, guardians did not report any statistically significant difference based on the type of provider.

#### Communication quality: Additional communication tools

Guardians who were provided with additional communication tools (pamphlets, notes, internet sources, and others) about FP, were more satisfied with the quality of information they received than the respondents who were provided with only verbal information sources (Fig. 2-A,  $p = 0.04$ ). However, the responses from patients did not show any statistically significant differences on the information quality based on the type of information provided (Fig. 2-B,  $p = \text{N.S.}$ ).

#### Communication Quality: Number of Consult Sessions

Compared with others, patients (15/32, 46.8%) who attended two or more consults reported that the consults were easier to understand (Fig. 2-A,  $p = 0.017$ ). Guardians (15/32, 47%) who attended two or more discussions also reported that information quality (Fig. 2-B,  $p = 0.024$ ) and communication quality (Fig. 2-C,  $p = 0.044$ ) during FP discussions were better. Data from both respondent groups in part reveals why only 47% of patients understood the concept of FP after their first discussion.

## Discussion

This study evaluated the quality of FP discussions based on their specific detailed features and satisfaction rates measured by the respondents—AYA patients and their guardians in Korea. We discovered that both patients and guardians were generally satisfied with the FP discussion, although several improvements can be made to better the quality of FP discussions.

The FP discussions in this study were commonly held in hospital hallways or at the patient's bedside in the presence of other patients. This meant that unrelated people could potentially overhear the details of their discussion. AYA patients have unique medical and psychosocial concerns, and they have to be provided with age-appropriate information, education and discussion [13, 14]. Therefore, an environment wherein their privacy is not protected should be avoided. Nevertheless, and strikingly, patients and guardians reported high levels of satisfaction with the respect they received and the protection of their privacy during the discussion (represented in questions 9 and 10). Moreover, respondents did not report different satisfaction rates between private rooms and relatively public spaces. This perception of privacy in the hospital environment is considered partly as the result of cultural difference [15]. Generally, most patients attending FP discussion, report that the communication is emotionally supportive for them. However, some patients experience negative feelings such as humiliation, psychological stress, or emotional challenges during FP discussion [12]. A substantial proportion of the patients prefer the conversation to be held in a private environment without the presence of their parents [16]. Although satisfaction was not different whether the privacy was protected or not in this study, medical privacy should be protected in general [17, 18]. Therefore, the setting for discussion should be improved for better quality of FP discussions.

In this study, respondents were more satisfied when FP discussions were provided by a doctor than provided by other types of counselors. This might be because pediatric or medical oncologists, and/or the gynecologists met patients in fertility preservation clinics. Thus, they delivered up-to-date knowledge and a rich experience on the strengths and weaknesses of FP during the counseling sessions. This may explain why patients who were counseled by physicians reported they received greater quality of information and good communication quality during the FP discussion in our study. The reason the patients and guardians favored the physicians rather than other type of providers might be the consideration of authority or power in the medical practice environment. There are differences in the success and effectiveness of FP discussions based on the identity of the counselor. The helpfulness of discussion is generally rated high with professionals including oncologists and gynecologists rather than with general practitioners or counselors[19]. Although FP success rates were irrelevant to the identity of the counselor, the completeness of the information content affected the success rate of FP [13].

Respondents who were counseled more than once expressed greater quality of FP discussion in this study. A single session of discussion may not only provide insufficient details on fertility preservation but also risk bombarding the patients with too much information at once. Considering the brief window of time available for patients between the diagnosis of cancer and chemotherapeutic treatment, an establishment of an efficient referral protocol that patients can follow may overcome this problem. The important thing is not only the number of discussions, but the quality of information and education delivered to the patients and families. To facilitate effective and high-quality communication, it is important to use various types of education materials. A study by Bradford et al. showed that a bundled intervention including a set protocol for referrals improved the documented outcomes for FP[20]. Developed set protocols are being increasingly introduced, such as the *Pathways* protocol set for female cancer patients by Woodard et al. which included seminars and telephone counseling with traditional face-to-face discussions with specialists [21]. Previous studies have shown that educational tools and materials improve understanding of the subject for patients. Allingham et al. and Tam et al. demonstrated that FP pamphlets improved fertility knowledge for patients compared to solely using verbal communication to explain FP [22, 23]. Likewise, our study showed that respondents who were offered additional educational tools such as notes, pictures, pamphlets, or internet sources reported greater quality of information.

To enhance the FP discussion, a multidisciplinary team should be organized[24]. Physicians and trainees on FP should also be provided with learning sessions. The referral pathway also has to be modified and improved according to the results and feedback obtained from this survey. In this study, in most cases, the number of discussions was less than two and the duration of each discussion was less than 10 minutes. The types of main counselors were diverse across study participants. A substantial proportion of patients and guardians had not heard of FP options previously. Collectively, these findings meant that most of the patients and guardians were new to the concept of FP when the cancer was diagnosed, and the FP discussions for each patient and family were not provided in a multidisciplinary manner; rather, there was one-way transmission of information from the counseling personnel to the patient or guardian. Importantly, these circumstances might not be able to provide discussions regarding fertility issues

specific to psychosocial support. Many medical institutions and professionals experience barriers during FP discussions in real world situations due to the lack of up-to-date knowledge on FP by clinicians, the limited time available for FP discussion before the start of the cancer treatment, and the limited FP options for female cancer patients [7]. The patients also need emotional support during the decision-making process regarding this sensitive topic [5]. For the FP discussion to be more effective, all the above issues should be acknowledged and improved.

This study has limitations, one of which is that the validity of our data is limited by the small sample size. This was due to the narrow pool of AYA cancer patients who have attended previous FP discussions. Additionally, this study was undertaken in a single institution, and thus cannot be generalized to global experiences about FP. However, this study is the first step for improving medical communication quality on FP issues for AYA patients and caregivers in Korea. The findings of this study reflect the medical environment specific to Korea in some senses. We hope this finding of our study to be a cornerstone for establishing the FP discussion among Korean AYA patients.

## **Declarations**

### **Funding**

None

### **Ethics approval and consent to participate**

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the institutional review board at Severance Hospital, YUHS (IRB no. 4-2019-0868).

### **Consent for publication**

Informed consent for publication submission was obtained from all individual participants included in the study.

### **Conflict of interest/Competing interest**

None of the authors have any conflicts of interest or competing interest to declare.

### **Author Contributions**

Jung Woo Han contributed to the study conception and design. Yoo Sub Shin made the first draft of survey materials. Seung Yeon Kwon, Seung Min Hahn, Won Kee Ahn and Chuhl Joo Lyu contributed the material preparation. Seung Yeon Kwon, and Seung Min Hahn advised on the study concept and design. Material preparation, survey and data collection were performed by Yoo Sub Shin and Mi Na Park. The data analysis were performed by Jung Woo Han, and Yoo Sub Shin. The first draft of the manuscript was written by Yoo Sub Shin, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

## Data availability

N/A

Code availability

N/A

## References

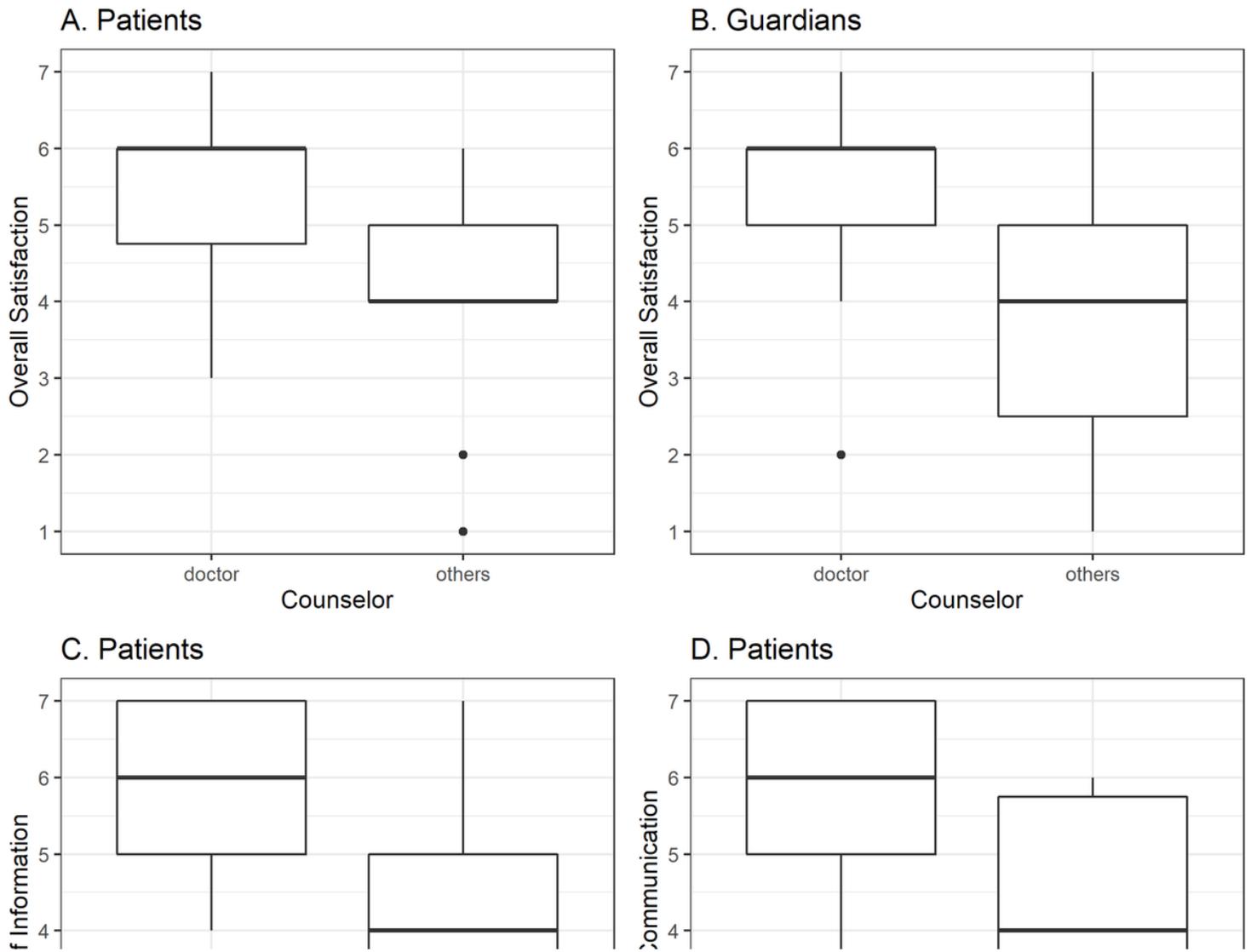
1. Murphy D, Klosky JL, Reed DR, Termuhlen AM, Shannon SV, Quinn GP (2015) The importance of assessing priorities of reproductive health concerns among adolescent and young adult patients with cancer. *Cancer* 121:2529–2536
2. Oktay K, Harvey BE, Partridge AH, Quinn GP, Reinecke J, Taylor HS, Wallace WH, Wang ET, Loren AW (2018) Fertility Preservation in Patients With Cancer: ASCO Clinical Practice Guideline Update. *J Clin Oncol* 36:1994–2001
3. Ataman LM, Rodrigues JK, Marinho RM, Caetano JP, Chehin MB, Alves da Motta EL, Serafini P, Suzuki N, Furui T, Takae S, Sugishita Y, Morishige KI, Almeida-Santos T, Melo C, Buzaglo K, Irwin K, Wallace WH, Anderson RA, Mitchell RT, Telfer EE, Adiga SK, Anazodo A, Stern C, Sullivan E, Jayasinghe Y, Orme L, Cohn R, McLachlan R, Deans R, Agresta F, Gerstl B, Ledger WL, Robker RL, de Meneses ESJM, Silva LH, Lunardi FO, Lee JR, Suh CS, De Vos M, Van Moer E, Stoop D, Vloeberghs V, Smitz J, Tournaye H, Wildt L, Winkler-Crepaz K, Andersen CY, Smith BM, Smith K, Woodruff TK (2016) Creating a Global Community of Practice for Oncofertility. *J Glob Oncol* 2:83–96
4. Speller B, Micic S, Daly C, Pi L, Little T, Baxter NN (2019) Oncofertility Decision Support Resources for Women of Reproductive Age: Systematic Review. *JMIR Cancer* 5:e12593
5. Anazodo A, Laws P, Logan S, Saunders C, Travaglia J, Gerstl B, Bradford N, Cohn R, Birdsall M, Barr R, Suzuki N, Takae S, Marinho R, Xiao S, Qiong-Hua C, Mahajan N, Patil M, Gunasheela D, Smith K, Sender L, Melo C, Almeida-Santos T, Salama M, Appiah L, Su I, Lane S, Woodruff TK, Pacey A, Anderson RA, Shenfield F, Ledger W, Sullivan E (2019) How can we improve oncofertility care for patients? A systematic scoping review of current international practice and models of care. *Hum Reprod Update* 25:159–179
6. Anazodo A, Ataman-Millhouse L, Jayasinghe Y, Woodruff TK (2018) Oncofertility-An emerging discipline rather than a special consideration. *Pediatr Blood Cancer* 65:e27297
7. Kohler TS, Kondapalli LA, Shah A, Chan S, Woodruff TK, Brannigan RE (2011) Results from the survey for preservation of adolescent reproduction (SPARE) study: gender disparity in delivery of fertility preservation message to adolescents with cancer. *J Assist Reprod Genet* 28:269–277
8. Harzif AK, Santawi VPA, Maidarti M, Wiweko B (2019) Investigation of Each Society for Fertility Preservation in Asia. *Front Endocrinol (Lausanne)* 10:151
9. Zhao Y, Zhang X, Zubizarreta ME, Xia Y, Li Y, Zhang X, Sheng M, Song Q, Xiao S (2020) A Survey Study Reveals the Positive Impact of Oncofertility Knowledge and Attitude on Oncofertility Practice

Among Oncologists in China. *J Adolesc Young Adult Oncol*

10. Ussher JM, Parton C, Perz J (2018) Need for information, honesty and respect: patient perspectives on health care professionals communication about cancer and fertility. *Reprod Health* 15:2
11. Anazodo A, Laws P, Logan S, Saunders C, Travaglia J, Gerstl B, Bradford N, Cohn R, Birdsall M, Barr R, Suzuki N, Takae S, Marinho R, Xiao S, Qiong-Hua C, Mahajan N, Patil M, Gunasheela D, Smith K, Sender L, Melo C, Almeida-Santos T, Salama M, Appiah L, Su I, Lane S, Woodruff TK, Pacey A, Anderson RA, Shenfield F, Ledger W, Sullivan E (2018) How can we improve oncofertility care for patients? A systematic scoping review of current international practice and models of care. *Hum Reprod Update* 25:159–179
12. Edge B, Holmes D, Makin G (2006) Sperm banking in adolescent cancer patients. *Arch Dis Child* 91:149–152
13. Wyns C, Collienne C, Shenfield F, Robert A, Laurent P, Roegiers L, Brichard B (2015) Fertility preservation in the male pediatric population: factors influencing the decision of parents and children. *Hum Reprod* 30:2022–2030
14. Coccia PF, Pappo AS, Beaupin L, Borges VF, Borinstein SC, Chugh R, Dinner S, Folbrecht J, Frazier AL, Goldsby R, Gubin A, Hayashi R, Huang MS, Link MP, Livingston JA, Matloub Y, Millard F, Oeffinger KC, Puccetti D, Reed D, Robinson S, Rosenberg AR, Sanft T, Spraker-Perlman HL, von Mehren M, Wechsler DS, Whelan KF, Yeager N, Gurski LA, Shead DA (2018) Adolescent and Young Adult Oncology, Version 2.2018, NCCN Clinical Practice Guidelines in Oncology. *J Natl Compr Canc Netw* 16:66–97
15. Kaya N, Weber MJ (2003) Cross-cultural differences in the perception of crowding and privacy regulation: American and Turkish students. *J Environ Psychol* 23:301–309
16. Ginsberg JP, Ogle SK, Tuchman LK, Carlson CA, Reilly MM, Hobbie WL, Rourke M, Zhao H, Meadows AT (2008) Sperm banking for adolescent and young adult cancer patients: sperm quality, patient, and parent perspectives. *Pediatr Blood Cancer* 50:594–598
17. Institute of Medicine Committee on Health R, the Privacy of Health Information: The HPR (2009) The National Academies Collection: Reports funded by National Institutes of Health. In: Nass SJ, Levit LA, Gostin LO (eds) *Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research*. National Academies Press (US) Copyright © (2009) National Academy of Sciences., Washington (DC)
18. Cockcroft S, Rekker S (2015) The relationship between culture and information privacy policy. *Electronic Markets* 26
19. Tschudin S, Bunting L, Abraham J, Gallop-Evans E, Fiander A, Boivin J (2010) Correlates of fertility issues in an internet survey of cancer survivors. *J Psychosom Obstet Gynaecol* 31:150–157
20. Bradford NK, Walker R, Henney R, Inglis P, Chan RJ (2018) Improvements in Clinical Practice for Fertility Preservation Among Young Cancer Patients: Results from Bundled Interventions. *J Adolesc Young Adult Oncol* 7:37–45
21. Woodard TL, Hoffman AS, Crocker LC, Holman DA, Hoffman DB, Ma J, Bassett RL, Leal VB, Volk RJ (2018) Pathways: patient-centred decision counselling for women at risk of cancer-related infertility:

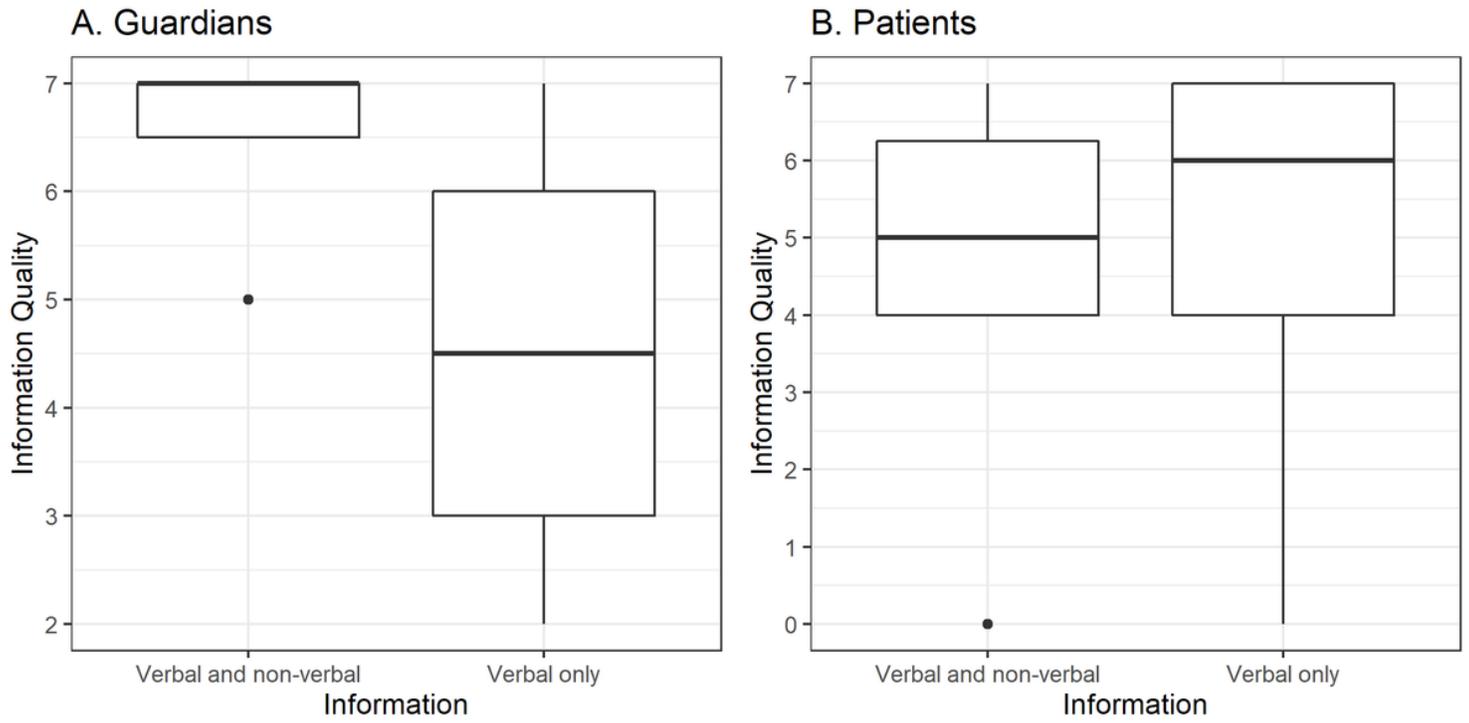
- a protocol for a comparative effectiveness cluster randomised trial. *BMJ Open* 8:e019994
22. Tam S, Puri N, Stephens D, Mitchell L, Giuliani M, Papadakos J, Gupta AA (2018) Improving Access to Standardized Fertility Preservation Information for Older Adolescents and Young Adults with Cancer: Using a User-Centered Approach with Young Adult Patients, Survivors, and Partners to Refine Fertility Knowledge Transfer. *J Cancer Educ* 33:528–535
  23. Allingham C, Gillam L, McCarthy M, Zacharin M, Jayasuriya S, Heloury Y, Orme L, Sullivan M, Peate M, Jayasinghe Y (2018) Fertility Preservation in Children and Adolescents With Cancer: Pilot of a Decision Aid for Parents of Children and Adolescents With Cancer. *JMIR Pediatr Parent* 1:e10463
  24. Ben-Aharon I, Abir R, Perl G, Stein J, Gilad G, Toledano H, Elitzur S, Avrahami G, Ben-Haroush A, Oron G, Freud E, Kravarusic D, Ben-Arush M, Herzog G, Yaniv I, Stemmer SM, Fisch B, Ash S (2016) Optimizing the process of fertility preservation in pediatric female cancer patients - a multidisciplinary program. *BMC Cancer* 16:620

## Figures



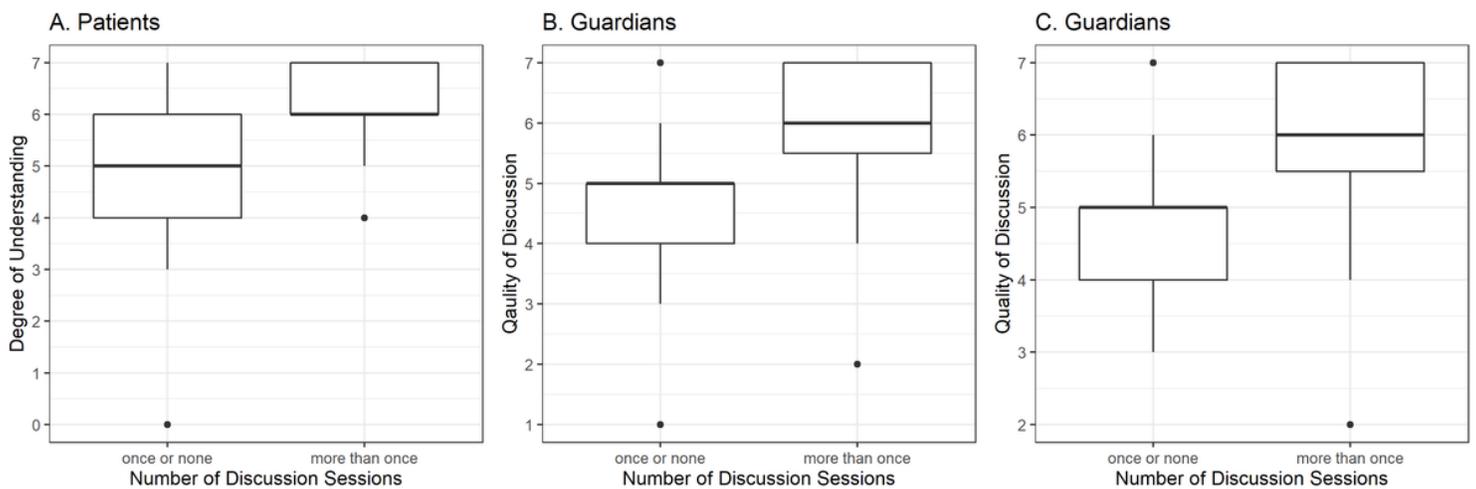
**Figure 1**

Patients' and guardians' evaluation on overall satisfaction with the communication process and the quality of communication by type of information provider. A. Patients' overall satisfaction of FP discussion ( $p = 0.015$ ). B. Guardians' overall satisfaction of FP discussion ( $p = 0.015$ ). C. Patients' evaluation of the information quality of the discussion ( $p = 0.001$ ). D. Patients' evaluation of the communication quality of the discussion



**Figure 2**

The evaluation of communication quality by the additional non-verbal information tools on fertility preservation. A. Guardians' responses on the degree of information quality rated by the type of information ( $p = 0.04$ ). B. Patients' responses on the degree of information quality rated by the type of information



**Figure 3**

Factors influenced by additional discussion sessions. A. Patients responded that they were able to better understand the concept of FP when additional discussion sessions were held ( $p = 0.017$ ). Moreover, guardians experienced greater communication quality (Fig 3-B,  $p = 0.024$ ) and information quality (Fig 3-C,  $p = 0.044$ ) with additional discussion sessions