



# Development and Application of Advance Care Planning Workbooks to Facilitate Communication with Children and Adolescent Patients: A Pilot Test

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**Purpose:** This study presents the process of designing workbooks for advance care planning appropriate for the Korean cultural setting and describes actual case studies. **Methods:** This study focused on single inductive case studies of the utilization of an advance care planning workbook and recruited individual participants. **Results:** The workbook for adolescents contained six sessions and the workbook for children contained seven sessions. The workbook sessions led to four major discoveries: 1) considering the Korean cultural context, discussions on life and death must be held indirectly; 2) the role of the counselor as a supporter is crucial for the workbook to be effective; 3) the workbook must be accessible regardless of the seriousness of the illness; and 4) patients must be able to make their own choice between the workbook versions for children and adolescents. Six facilitating factors improved engagement: 1) the role of the counselor as a supporter; 2) building trust with the patient; 3) affirming freedom of expression on topics the patient wished to avoid talking about; 4) having discussions on what private information to keep secret and to whom the information can be disclosed; 5) discovering and regularly discussing relevant topics; and 6) regular communication and information-sharing with the patient's medical service providers. **Conclusion:** It is necessary to build on actual case studies regarding workbooks for children and adolescents in order to expand the usage of these workbooks to all relevant medical institutions in Korea.

**Key Words:** Palliative care, Hospice care, Pediatrics, Communication, Child, Adolescent, Young adult

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## INTRODUCTION

### 1. Background

With advances in medical technology, the survival rate of child and adolescent patients who are treated for life-threatening diseases is dramatically improving [1], but deaths from incurable and severe diseases continue to occur. Among all child and adolescent deaths (among individuals younger than 19 years) in South Korea in 2014, 35.8% of deaths (1,044

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individuals) were due to complex chronic diseases. Of these deaths, 41.3% were among newborn children (less than 1 year old), 37.4% among adolescents (ages 10 to 19), and 21.3% among children (ages 1 to 9) [2]. This suggests that there is a need to have direct discussions about advance care planning with children and adolescent participants who are able to communicate. Advance care planning with children and adolescents must be approached individually and sensitively with due consideration of participants' age and developmental characteristics [3].

Establishment of an advance care plan refers to the overall process of confirming the intention to receive medical treatments appropriate for one's current and expected health status and holding discussions on the goals of treatment and care between medical staff and the patient's family [4]. Advance care planning with children and adolescents respects the patient's and family members' preferences and autonomy in the treatment process, assists in achieving a clear understanding of future treatment plans, and facilitates communication about the diagnosis and prognosis. Such discussions increase the level of family members' satisfaction in caring for the patient, allow family members to feel more prepared for the circumstances of treatment, and alleviate stress, anxiety, and depression among family members experiencing loss; therefore, these discussions ultimately have a positive influence on the healthy grieving process after the patient's death [5,6]. Adolescents who experience advance care planning discussions prefer to organize their personal preferences through holding comfortable conversations, and this process helps parents to understand the patient's wishes [7].

In other countries, the need to implement advance care planning is emphasized as integral to end-of-life care for children and adolescents receiving treatment for life-threatening diseases [8]. Countries such as the United Kingdom, the United States, and Australia have recommended the development of a guideline for advanced care planning for children and adolescents through policies that support the activities of related societies and associations [9]. Many medical staff have reported that it is too late to begin advance care planning when patients are in a medical crisis [6], and have emphasized that patients should be given enough time to consider these issues by holding appropriate discussions on advance care planning earlier.

Adolescent patients, patients in their early 20s, and their family members would like to hear explanations that provide them with a sufficient understanding of the medical situation for them to participate in the decision-making process [10].

In order to effectively communicate with child and adolescent patients, one should discuss patients' perceptions of the disease and their emotional changes, help them understand their purpose of life, confirm their preferences regarding care and treatment, and, when necessary, document these processes [11]. A cooperative relationship should be maintained with parents, communication goals according to the patient's developmental stage should be established, and a differentiated strategy for each patient and family culture should be developed [12]. "Voicing My Choices" [13], "This is My World" [14], and "My Wishes" [15] are advance care planning workbooks that are frequently used internationally. These workbooks are psychological therapeutic tools designed to facilitate communication between counselors and child and adolescent patients regarding treatment. Advance care planning workbooks aim to start conversations about various aspects of the patient's life, including the patient himself or herself, family, friends, school, disease, and opinions about the future, and to facilitate a relationship with the patient [16].

In South Korea, the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life (hereinafter referred to as the Act on Decisions on Life-Sustaining Treatment) entered into force (in its most recently amended form) in March 2019. This act required changes in the clinical field for child and adolescent patients with severe diseases and emphasized the importance of advance care planning. In Article 10, Paragraph 3 of the Act on Decisions on Life-Sustaining Treatment, it is stipulated that for minor patients, before documenting the advance care plan, important information should be explained to the patient and his or her legal guardian. However, due to inadequate recognition of pediatric palliative care among medical staff, the negative perspectives of family members, and the financial burden, the expansion of pediatric palliative care has been delayed in South Korea [17]. Difficulties are experienced in discussing advance care planning due to challenges in predicting the timing of death for child and adolescent patients and social pressures regarding discussions about death [18]. Moreover, insufficient

research has been conducted in South Korea on needs for advance care planning among children and adolescents, and practical evaluations of cases in which advance care planning was conducted are lacking.

Therefore, this study presents the development of a workbook to facilitate the participation of child and adolescent patients in their advance care planning and suggests its application to provide foundational data with practical implications for future discussions about advance care planning among children and adolescents.

## 2. Purpose

The aim of this study was to develop and implement a workbook to facilitate the participation of child and adolescent patients receiving treatment for life-threatening diseases in the decision-making process for advance care planning.

- To develop an advance care planning workbook suitable for medical practice in South Korea based on children and adolescent advance care planning workbooks implemented abroad.
- To analyze case studies of advance care planning workbook utilization.

## METHODS

Based on the model designed by Borg and Gall [16], this

study is a methodological study that reviewed tools from abroad [13–15] to develop a workbook suitable for South Korean culture and reality, and is also an experimental study that applied the developed workbook to real cases. After developing the workbook, two qualitative, single, and inductive case studies using a methodology based on the constructivist paradigm, which allows the data to reflect various aspects of reality, were conducted [19]. In order to obtain results related to the research topic, an inductive method [20] was used, wherein the content of the advance care planning workbook drawn from the records of the pediatric palliative care team was used to generate concepts and topics.

## 1. Workbook development

Tools from other countries (“Voicing My Choices” [13], “This is My World” [14], and “My Wishes” [15]) were referenced for the development of the workbook. Seven experts in pediatric palliative care, including four doctors, two nurses, and one social worker, participated in the development. Meetings were held from May 2018 to February 2019, and the meeting topics and formats are shown in Table 1.

Considering the uniqueness of pediatric palliative care, which deals with the sensitive topic of discussions about dying, field and pilot tests were eliminated, but an attempt was made to compensate for this omission by strengthening the expert review process through team meetings. Therefore, this

Table 1. Workbook Development Meetings.

No	Meeting type	Meeting participants	Meeting content	Date
1	Face to face meeting	All members attended (4 doctors, 2 nurses, 1 social worker)	Selection of review materials	2018.06.05.
2		All members attended	Check information from IRB	2018.07.03.
3		All members attended	Discuss workbook content	2018.07.16.
4		All members attended	Discuss workbook content	2018.07.23.
5		All members attended	Discuss workbook content	2018.11.14.
6		All members attended	Discuss workbook content	2018.10.31.
7	Online meeting	All members attended	Kickoff meeting	2018.05.29.
8		All members attended	Share draft workbook designs	2018.11.09.
9		1 doctor, 1 social worker	Selection of a design company quote confirmation	2018.11.23.
10		2 doctors, 1 nurse, 1 social worker	Modify workbook design	2018.12.14.
11		2 doctors, 1 social worker	Discuss workbook content	2018.12.26.
12		1 doctor, 1 social worker	Discuss workbook content	2019.01.02.
13		1 doctor, 1 social worker	Discuss workbook content	2019.01.10.
14		2 doctors, 1 nurse, 1 social worker	Modify workbook design	2019.02.01.

study developed a workbook using five of the 10 development phases suggested by Borg and Gall [21]: 1) collecting data by analyzing situations abroad and the international literature, 2) establishing a development plan and a preliminary workbook format, 3) conducting an expert review and revisions through multidisciplinary expert group meetings, 4) preparing the final workbook format and implementation, and 5) outlining and disseminating instructions for use.

## 2. Utilization of the workbook

### 1) Participants' characteristics

The inclusion criteria for participants were pediatric palliative care patients who used the child advance care planning workbook with consent from their parents. Among 18 patients who used either the adolescent or the child version of the advance care planning workbook through the Seoul National University Children's Hospital Pediatric Palliative Care team from September 2019 to March 2020, two patients (one adolescent and one child) who verbally agreed to participate in the study were included in the final analysis.

### 2) Data collection period and procedures

The data collection period for this study was from March 2019, when the advance care planning workbook was developed, to March 2020. Approval from the institutional review board of the researchers' institution was obtained (H-1807-184-962), and participants were recruited. A single case each was recruited for the child version and adolescent version of the advance care planning workbook, resulting in a total of two participants.

### 3) Data analysis

The content of each patient's engagement with the workbook and the patient's health records were analyzed retrospectively. The use of the workbook was analyzed using details from the pediatric palliative care team records. Information was extracted from patient's health records on demographic characteristics, location of death, the advance care plan, and whether cardiopulmonary resuscitation; vasopressor, analgesic, or anticancer drug administration; artificial respiration, continuous renal replacement therapy, hemodialysis, or discontinuation of life-sustaining treatment was conducted. One pediatric doctor,

one pediatric palliative care specialty nurse, and one dedicated social worker analyzed and organized the content based on the consultation records. Triangulation and member-checking were used to establish the trustworthiness of the study.

## RESULTS

### 1. Workbook development

#### 1) Results from the five phases of development

##### (1) Data collection through analyses of the situation abroad and the relevant literature

The basic content of the children and adolescent advance care planning workbook was composed based on the workbooks in use abroad. Specifically, the "Voicing My Choices" [13] and "My Wishes" [15] workbooks used by Aging with Dignity and the "This is My World" [14] workbook developed by the United States National Institutes of Health were checked to extract the main characteristics of advance care planning discussions with child and adolescent patients.

##### (2) Development plan and preliminary format of the workbook

Based on the content extracted from the basic materials that were consulted for the development of this workbook, a development plan and the format of the workbook were devised. The detailed content was updated based on the guidelines suggested in "My Wishes & Voicing My Choices: A Planning Guide" [22] and composed with consideration of the reality and cultural setting of South Korea. "My Wishes" [15] was used as the primary reference for the child version, and "Voicing My Choices" [13] for the adolescent version. "My Wishes" [15] is a workbook developed for children under the age of 13, and its suggestions were adopted regarding how the family, caretaker, or counselor can start the conversation with children and how children can express their emotions more easily. "Voicing My Choices" [13] is a workbook designed for adolescents and young adults that mainly suggests a process for family, friends, and the main caretaker to understand and communicate their preferences. The content was revised to include important values in the treatment process in the South Korean context.

**Table 2.** Advanced Care Planning Workbook for Children and Youth.

Version 1_ children's version	
Target age group (recommended age)	Under the age of 13 (from age 5 to higher elementary school grade students)
Purpose	The workbook is designed to guide the patient as he or she decorates an imaginary garden, helping him/her to be interested in and to easily perceive and understand the treatment procedure. If the patient shows cognitive performance between age 5 and lower elementary school grade level, the My Garden Workbook for Children may be used.
Workbook content in detail	<ol style="list-style-type: none"> <li>1. Seed. "Everything About Me"                             <ul style="list-style-type: none"> <li>- Self-introduction, drawing people who are special to me</li> <li>- Goal: Provide an opportunity for counselors and patients to build rapport at the beginning of the workbook</li> <li>- Helps the patient to easily and naturally introduce himself or herself by filling in the blanks</li> </ul> </li> <li>2. Sprout. "Controlling My Emotions"                             <ul style="list-style-type: none"> <li>- Face different emotions, build "my own space"</li> <li>- Goal: Expect to be able to feel psychological stability while expressing the main emotions the patient has recently felt and creating a safe space of his or her own</li> <li>- Tips for counselors: Use emotion stickers to proceed. When building "my own safe space", the reason and meaning of creating "my own safe space" suggested in the workbook can be explained to the patient to enhance his or her understanding</li> </ul> </li> <li>3. Blossoming Tree. "How Was My Day?"                             <ul style="list-style-type: none"> <li>- Rating pain, managing daily activities at home and one's own health</li> <li>- Goal: Expect to determine whether the patient feels uncomfortable in daily life and to assess his or her the surrounding support system</li> </ul> </li> <li>4. Wind. "Staying Comfortable at the Hospital"                             <ul style="list-style-type: none"> <li>- Rating pain, managing daily activities at the hospital and one's own health, understanding the disease</li> <li>- Goal: To explain the patient's disease to the patient, and to confirm how well the patient understands and accepts his or her medical situation</li> </ul> </li> <li>5. Drizzle. "Time for Growth"                             <ul style="list-style-type: none"> <li>- Discuss good and bad memories, imagining the future</li> <li>- Goal: To help patients receive emotional support by encouraging them to share their experiences in their daily lives</li> </ul> </li> <li>6. Clouds. "A Magical Space"                             <ul style="list-style-type: none"> <li>- Miracle questions (e.g., What would you do if you have superpowers? What would you do if you become a powerful leader? If you have a mirror that shows only the truth, what would you ask? ), imagining a bright future</li> <li>- Goal: To provide an opportunity for patients to manage their mood by using the miracle question to escape from the current limited treatment environment</li> </ul> </li> <li>7. Sunshine. "This is How I Want to be Taken Care of"                             <ul style="list-style-type: none"> <li>- Understand the patient's specific desires for care (multiple-choice questions and short-answer questions are used for an accurate understanding)</li> <li>- Goal: To help the patient consider future medical conditions and to identify the patient's individual care preferences</li> </ul> </li> </ol>
Examples	<div style="display: flex; flex-wrap: wrap;"> <div style="width: 50%;"> </div> <div style="width: 50%;"> </div> <div style="width: 50%;"> </div> <div style="width: 50%;"> </div> </div>

Table 2. Continued 1.

Version 2_ youth version (adolescents and young adults)	
Target age group (recommended age)	Age 13 and older (from middle school age to young adults)
Purpose	The purpose is the same as the children’s version. For patients showing cognitive abilities of higher-level elementary school students or older, My Garden Workbook for Youth may be used.
Workbook content in detail	<ol style="list-style-type: none"> <li>1. Seed. “Everything About Me” <ul style="list-style-type: none"> <li>- Drawing brain diagrams to make mind maps, self-introduction, drawing people who are special to me</li> <li>- Goal: Provide an opportunity for counselors and patients to build rapport at the beginning of the workbook</li> </ul> </li> <li>2. Sprout. “Controlling My Emotions” <ul style="list-style-type: none"> <li>- Face different emotions, build “my own space,” talk about a safe place</li> <li>- Goal: Expect to be able to feel psychological stability while expressing the main emotions the patient has recently felt and creating a safe space of his or her own</li> <li>- Tips for counselors: Use emotion cards to proceed. When building “my own safe space”, the reason and meaning of creating ‘my own safe space’ suggested in the workbook can be explained to the patient to enhance his or her understanding</li> </ul> </li> <li>3. Blossoming Tree. “My Daily Activities” <ul style="list-style-type: none"> <li>- Managing health conditions at home and rating the day, planning the future</li> <li>- Goal: Expect to determine whether the patient feels uncomfortable in daily life and to assess the surrounding support system</li> </ul> </li> <li>4. Wind. “Staying Comfortable at the Hospital” <ul style="list-style-type: none"> <li>- Managing health conditions at the hospital and rating the day, awareness of the disease, assessing expectations for the hospital</li> <li>- Goal: To explain the patient’s disease to the patient, and to confirm how well the patient understands and accepts the medical situation</li> <li>- In the youth version, life at home and in the hospital are marked with scores so that life satisfaction can be quantified</li> </ul> </li> <li>5. Drizzle. “My Life” <ul style="list-style-type: none"> <li>- Drawing a life curve, writing letters for one’s future self</li> <li>- Goal: To help patients receive emotional support by encouraging them to share their experiences in daily life</li> <li>- In the youth version, it is possible to think about the past, present, and future time by using the life curve and writing a letter to themselves</li> </ul> </li> <li>6. Clouds. “If I’m in This Situation” <ul style="list-style-type: none"> <li>- Miracle questions (e.g., What would you do if you have superpowers? What would you do if you become a powerful leader? If you have a mirror that shows only the truth, what would you ask? What would you do if you can see the future? If you could meet anyone you want, who would you meet, and what would you do?)</li> <li>- Goal: To provide an opportunity for patients to manage their mood by using the miracle question to escape from the current limited treatment environment</li> <li>&gt;Conditional questions (What would you do if you are sick? What would you do if you feel low?)</li> </ul> </li> <li>7. Sunshine. “Making Decisions for the Future” <ul style="list-style-type: none"> <li>- Understand the patient’s desire for health and care (multiple-choice questions and short-answer questions are used to obtain an accurate understanding. The workbook will also prompt conversations on the patient’s detailed plans on Advance Care Planning), understanding what the patient wants, hearing the patient’s perspectives on spirituality, and talking about what the patient wants</li> <li>- Goal: To help the patient consider future medical conditions and to identify the patient’s individual care preferences</li> <li>- Tips for counselors: Counselors should understand the patient’s level of knowledge about his or her medical situation, whether they want to receive an explanation, and how much they want to participate in decision-making, and apply them when discussing advanced care planning.</li> </ul> </li> </ol>
Key difference of adolescent workbooks, compared to the child version	Inclusion of various questions that prompt deeper thinking. Especially in sessions 6, “If I’m in This Situation” and 7, “Making Decisions for the Future”, the book allows the patient to write down his/her plans for Advance Care Planning thoroughly.

Table 2. Continued 2.

Version 2_ youth version (adolescents and young adults)	
Examples	

**(3) Expert review and revision of workbook content through multidisciplinary expert group meetings**

After developing the preliminary workbook based on international guidelines, the content was revised and updated through group meetings with relevant experts, including a specialist who treats children and adolescents with severe illness, a pediatric psychiatrist, a pediatric palliative care specialist, and a hospice specialty nurse. The multidisciplinary experts discussed: 1) developing a workbook that would help participants freely express their emotions about their medical situation [22]; 2) the creation of separate child and adolescent versions so the workbook could be used age-appropriately [23]; and 3) suggesting ways to support communication and decision-making according to patients’ developmental stage and medical condition beyond only children and adolescents [3].

**(4) Final composition of the workbook and preparation for implementation**

Considering the characteristics of pediatric palliative care patients, the child and adolescent versions of the workbook were developed separately so that advance care planning could be discussed in an age-appropriate manner. Both versions included seven sessions: “seed”, “sprout”, “blossoming tree”, “wind”, “drizzle”, “cloud”, and “sunshine.” Upon finalization of the workbook, the child version was recommended for patients younger than 13 and the adolescent version for patients older than 14.

**(5) Preparation of workbook instructions and distribution**

So that counselors and patients can understand how to use the workbook, general instructions were given succinctly in the front page. After finalizing the development of the workbook, to share and advertise the workbook, data were uploaded to a freely accessible website [24], so that professionals at any institution in South Korea can easily obtain and use the workbook.

**2) Detailed content of the workbook for each session**

The content of the workbook consisted of the following components: introducing oneself, regulating one’s emotions, managing living habits and pain at home, managing living habits and pain at the hospital, looking back on life through a life chart, dreaming about the future, and understanding one’s health and care needs. The activities for each session are described in detail in Table 2.

**2. Results of workbook utilization**

**1) Analysis of workbook utilization and health records**

**(1) Utilization of the “My Own Garden” workbook**

After developing the advance care planning workbook, either the child or adolescent version was utilized by 18 patients. In these cases, the main counselor was a pediatric psychiatrist in seven cases, a dedicated social worker focusing on pediatric palliative care in 10 cases, and an art therapist in one case. The adolescent version was used more frequently, with 12 patients

(67%) using the adolescent version and six patients (33%) using the child version. In 11 cases (61%), advance care planning was discussed intensively at the end of life, while in seven cases (39%), the workbook was used to help patients regulate their emotions during treatment. It was thus confirmed that in the majority of cases, the workbook was used to discuss advance care planning when patients had entered the end-of-life stage.

**(2) Characteristics of participants who used the workbook**

Among the 18 patients who used the workbook from September 2019 to March 2020, two participants (one adolescent and one child) agreed to participate in the study (Table 3).

**2) Cases of workbook utilization**

**(1) Analysis of the procedure of workbook utilization**

The counseling records of the two cases were analyzed using an inductive method to extract ideas and themes. First, the topic of life and death was handled using the following framework: “create a safe space”, “use ‘if’ questions”, “what I want”, and “leave a footprint.” Participants responded to indirect questions regarding death and spoke about their values related to life and death.

Second, according to the counseling records, the counselor helped to achieve the goal of the session by explaining the sug-

gested material contained in the introduction before starting to use the workbook. The average duration of each workbook counseling session was 30 minutes, and due to aspects of patients’ medical situations such as pain and symptom management, the counselor made short but frequent visits.

Third, participants selected whether they wanted to use the child version or the adolescent version of the workbook. Patient A, who selected the child version, was at the beginning of adolescence, but the patient felt that using the adolescent version was stressful and preferred to use the child version, which has pictures and stickers and is simpler to use. Therefore, the process was changed to accommodate the patient’s preference.

**(2) Patient A**

**① Details of disease**

Patient A was a 22-year-old male patient. At age 2, after being diagnosed with functional single ventricle, he underwent several heart operations. At the time of the first interview, he was not able to speak due to a tracheostomy, but he was able to communicate through blinking his eyes, mouthing words, and nodding his head. Patient A died in the pediatric intensive care unit (ICU) 60 days after completing the workbook.

The medical status of patient A deteriorated rapidly after Fontan surgery failed, and he was referred by his primary

**Table 3.** Characteristics of Participants.

Patient	Sex	Age	Education level	Diagnosis (department)	Notable events in disease progression (treatment period)	Date of referral to pediatric palliative care team	Date of death (location)	Workbook starting date	Communication ability
A	Male	22	2-year college graduate	Functional single ventricle (Q204) (pediatric department, critically ill patient)	Diagnosed: March 1998 Worsened: February 2019 (21 yrs)	February 6, 2019	July 12, 2019 (PICU)	March 27, 2019	- Patient unable to speak after receiving tracheostomy - Could communicate by nodding, blinking, mouthing words, using AAC boards - Could communicate with counselor’s assistance
B	Female	12	Attending elementary school	Rhabdomyosarcoma (pediatric department, hematologic malignancy)	Diagnosed: April 2016 Recurrence: May 2018 (4 yrs)	May 30, 2018	Mar 27, 2020 (general Ward)	February 12, 2020	- No notable problems in communication - Patient unable to write due to pain and needed counselor’s help



medical team in the pediatric ICU to the pediatric palliative care team. In March 2019, after explaining the content and purpose of the advance care planning workbook and with consent from the patient and his caretaker, he completed the workbook. When patient A started to complete the workbook, his blood pressure was around 63/40 mmHg, he was receiving vasopressors and painkillers (dopamine [10  $\mu$ g/kg/min], epinephrine [0.2  $\mu$ g/kg/min], dobutamine [5  $\mu$ g/kg/min], and fentanyl [1  $\mu$ g/kg/hr]), he was on a ventilator and continuous renal replacement therapy, and discontinuation of life-sustaining treatment had not been discussed. After completing the workbook, the patient decided not to receive resuscitation and filled out life-sustaining treatment forms number 9, 12, and 13 after discussing the topic with the attending physician from the pediatric palliative care team and his parents. After additional discussions on July 12, it was decided to discontinue vasopressors and to remove the patient from the ventilator. Patient A died surrounded by all of his family members, and his disease trajectory is presented in Figure 1.

② Details of discussions about advance care planning

Patient A’s medical situation, in which his verbal communication was limited due to a tracheostomy and the use of pain medication, made it necessary for the counselor to find the right time to have discussions. In session 3, the patient’s desire to continue using available life-sustaining medical interventions was understood. His wish to not know when his medical situation would deteriorate and to primarily communicate with his main caretaker was also confirmed. The goal of using the workbook was achieved in the sense that the main decision-

maker following future deterioration in the patient’s medical status was pre-identified. The specific counseling details are presented in Table 4.

(3) Patient B

① Details of disease

Patient B was a 12-year-old female patient. After the recurrence of rhabdomyosarcoma in May 2018, she was referred to the pediatric palliative care team by her primary medical team. At the time of the first visit in February 2020, the patient was able to communicate verbally, but experienced severe pain. The counselor filled out the workbook on the patient’s behalf after understanding what the patient wished to communicate. Patient B died in the general ward 30 days after completing the workbook.

As for the details of patient B’s disease, she was diagnosed with rhabdomyosarcoma in April 2016 and completed surgery and chemotherapy. However, the cancer returned 5 months after the completion of chemotherapy. After the relapse, fentanyl 300 ( $\mu$ g/hr) and ketamine 8 (mg/hr) were given for supportive care and pain management starting in August 2019. After the completion of radiation therapy, olaparib- or paclitaxel-based chemotherapy was considered, and she was not on any vasopressors, ventilation, or continuous renal replacement therapy. After using the workbook, transfer to a hospice was planned based on discussions with the pediatric palliative care team. After discussions with the attending physician, parents, and the patient, life-sustaining treatment forms number 1, 9, and 13 were completed on February 18, and the decision

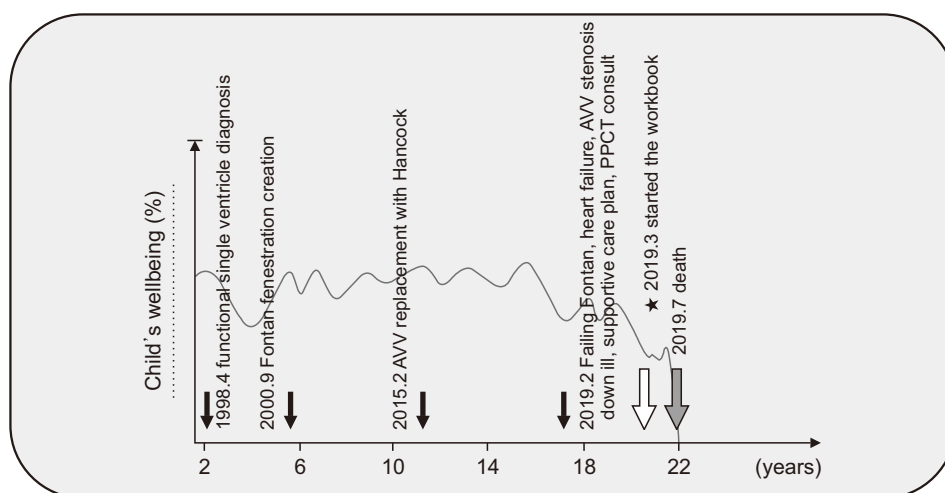


Figure 1. Detailed disease trajectory of patient A.

**Table 4.** Advance Care Planning Workbook Details of Patient A.

Session	Details
Consent before starting the workbook	Date and time of meeting: 2019.03.27., 14:00 <ul style="list-style-type: none"> <li>- Workbook guidance and consent process for the patient’s mother and the patient</li> </ul>
1st session	Date and time of meeting: 2019.04.05., 14:30~15:00 <ul style="list-style-type: none"> <li>- Communication ability: unable to speak after receiving tracheostomy, could communicate by nodding, blinking, mouthing words, using AAC boards, could communicate with counselor’s aid</li> </ul>
Could not proceed	Date of visit: 2019.04.09., 2019.04.18. <ul style="list-style-type: none"> <li>- Visited for counseling, but could not proceed during sleep or due to the patient’s health condition</li> </ul>
2nd session	Date and time of meeting: 2019.04.25., 11:00~11:30 <ul style="list-style-type: none"> <li>- The patient was receiving analgesics for pain control, so was often sleeping during the visit</li> <li>- The patient was very sleepy, but expressed his willingness to continue making his own garden. He continued to doze off even when answering the questions. We waited a little for him to wake up and proceeded with counseling again</li> <li>- Talked about his feelings, such as his current interests (eating, discharging), feeling frustrated by fasting, boredom while lying down, and anxiety about not being discharged. His current status was reported as “It is frustrating, but not very difficult.”</li> <li>- Self-introduction (marked as a slow but persistent person and asked to draw a turtle)</li> <li>- Confirmation of his values (“I think that the most important thing in my life is ‘expression’. I want to express my gratitude to my family, and I work on drawing family pictures.”)</li> </ul>
Could not proceed	Date of visit: 2019.04.29., 2019.05.07. <ul style="list-style-type: none"> <li>- Visited to consult him, but immediately fell asleep after answering a question and could not proceed</li> <li>- Considering the patient’s medical situation, it was thought that it would be difficult to conduct additional counseling sessions, and it was planned to discuss advance care planning in the next session</li> </ul>
3rd session	Date and time of meeting: 2019.05.10., 16:00~16:45 <ul style="list-style-type: none"> <li>- Talked about the patient’s wishes related to advance care planning and care</li> <li>- “People around me tell me that I sleep a lot lately, but I feel that I am not sleeping enough.”</li> <li>- Living at the hospital was 50 out of 100. He said if he could sleep, while together with his mother, and family, it would improve to 100 points</li> <li>- If he encountered a mirror that tells the truth, he wanted to ask if he can be healthy</li> <li>- He talked about his desire to eat fruit, and other types of food, and a few days ago, his mother cut some candy into small pieces and put it in his mouth to taste</li> <li>- If he can invite someone to his own space to talk, he would like to talk with “Mom”, and if he could change something, he would like to change “his health”</li> <li>- If his physical condition deteriorates, he stated that he would like to stay at home. He explained that he was not happy because he could not leave the intensive care unit</li> <li>- What he really wanted was, “I want to be with my family as much as possible, and when someone visits, I want them to wake me up if I’m sleeping. I want to spend time with my family while I am at the offcietel.”</li> </ul>
4th session	Date and time of meeting: 2020.05.12., 11:00~11:25 <ul style="list-style-type: none"> <li>- When asked, “If my physical condition suddenly deteriorates, is there anything I would not like to do about it?” He strongly denied this possibility, and expressed his strong will to be actively treated to the end with all possible treatments</li> <li>- However, if his medical situation does not get much better, he did not want to let him know instead he wanted to communicate with his mother</li> <li>- The footprint he wanted to leave was “time with family”. Considered writing a letter to his family</li> </ul> <p>Shared the advanced care planning discussed with the patient with the patient’s mother, the pediatric palliative care team, and the intensive care unit’s primary care physician</p> <ul style="list-style-type: none"> <li>- Termination and compensation</li> <li>- After completing all the workbooks, the patient signed the last page and decided how to commemorate its completion. It was Parents’ Day yesterday, but he did not express it to his parents, so he specifically explained the gift he wanted to give to his mom and had it delivered</li> </ul>

Table 4. Continued.

Session	Details
5th session (additional session)	<p>Date and time of meeting: 2020.05.31., 15:30~15:50</p> <ul style="list-style-type: none"> <li>- The patient was very satisfied with the discussion with the intensive care unit and the decision to start additional visits at 1, and 5 o'clock</li> <li>- Letter writing. It has been too long since he had seen his brother in the military, so he decided to write a letter and send it to his brother's place of service. He decided to consider what to write by next week</li> </ul>
6th session (additional session)	<p>Date and time of meeting: 2019.06.03., 10:30~11:00</p> <ul style="list-style-type: none"> <li>- Wrote a letter to his brother</li> <li>- He said that he did not have experience with letter-writing in general, so he did not know how to write it instead he briefly explained why he wrote the letter and what it contained</li> <li>- He pondered for a long time and expressed his stories in a few words. The counselor completed the letter, writing it according to what the patient said (letter omitted)</li> <li>- He said that he wanted to send his family photo along with the letter, so he printed it and mailed it</li> </ul>
Detailed discussion of advanced care planning	<p>Date and time of meeting: 2019.07.11., 17:00~17:30</p> <p>As the patient's medical condition deteriorated, consultations were conducted regarding the suspension of life-sustaining medical treatment</p> <ul style="list-style-type: none"> <li>- When the patient was conscious, the family conveyed words of love, remorse, and gratitude, and said that the patient nodded at the words of love. His brother also tried to endure the tears, but told him that he was so sad that he might need counseling later. In this regard, it is necessary to take full advantage of the available community resources</li> <li>- Discussed opinions between the main team and the pediatric palliative care team. The patient's parents decided not to make the patient's life anymore difficult, and thus, they conveyed the opinion that they decided to stop the life-sustaining medical treatment (i.e., to discontinue vasopressors) was made. We decided to set aside time before proceeding to stop the medication that was being given to the patient, as the patient may die immediately</li> <li>- We asked the primary care physician to fill out form number 12, and discussed plans to stop the vasopressor after the next morning's interview</li> </ul>

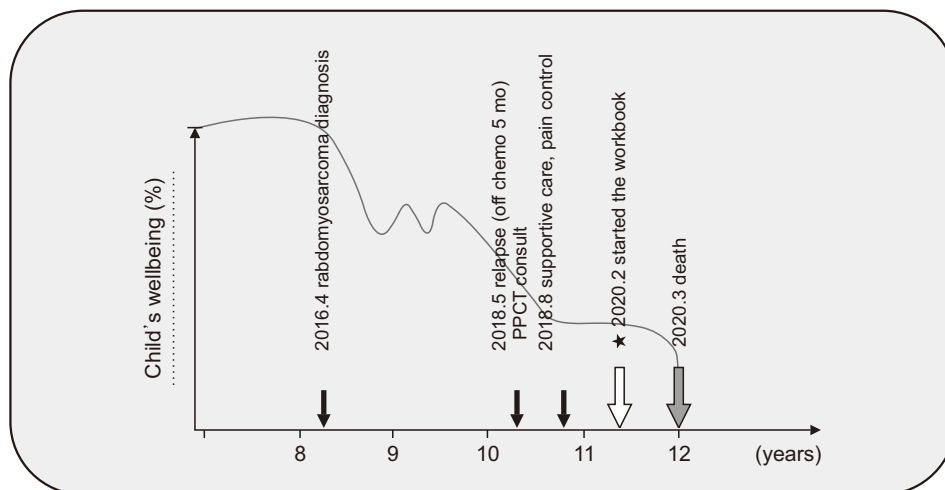


Figure 2. Detailed disease trajectory of patient B.

was made not to intubate the patient, perform CPR, or administer additional chemotherapy. Patient B died in a private room in the general ward on March 27, 2020. The detailed progression of her disease is presented in Figure 2.

② Details of discussions about advance care planning

Patient B was taking pain medication and was not in a suit-

able physical condition to engage in the workbook discussions each time the counselor visited. The counselor made regular visits, and the workbook was completed after nine visits. The expected outcome from the workbook was achieved, as the workbook facilitated communication by becoming a means through which the patient could communicate about her level

of pain and symptoms (vomiting) to the medical staff. Discussions about life-sustaining treatment were focused on during sessions 4 to 6, and the care and communication format pre-

ferred by the patient was understood. The counseling procedure is presented in detail in Table 5.

**Table 5.** Advance Care Planning Workbook Details of Patient B.

Session	Details
Consent before starting the workbook	Date and time of meeting: 2020.02.12., 16:00 - Workbook guidance and consent process for the patient’s mother and the patient
1st session	Date and time of meeting: 2020.02.13., 10:00~10:20 - Self-introduction (12 pictures by the age of the yellow petals). After writing the name of the patient, her parents, her grandmother, and her favorite “making,” the patient stated that her condition was not good and the session ended early
2nd session	Date and time of meeting: 2020.02.14., 15:00~15:40 - The patient’s abdominal pain was so severe that it was impossible to bend her waist forward, so it was uncomfortable for her to write with a pen. After asking the counselor, the patient decided to proceed with the counselor’s assistance with writing and drawing instead - The patient was unable to write due to pain and needed the counselor’s help. A tumor in the stomach hurt her the most at that time - Drawing precious people (father, sister, mother, and the patient herself). A detailed request explaining the characteristics of each family member in detail. “I want to say to my family, ‘I love you.’” - In the handling of emotions, she expressed a smiley expression as a desired emotion, and recently reported feelings of crying “somewhat often” as a frequently felt emotion, and attached a crying sticker. She reports that she might feel good when consuming liquids or feeling comfortable > As motivation to finish the workbook, the reward to be provided upon completion was determined in advance. Specifically, she chose a paper doll she wanted to have
3rd session	Date and time of meeting: 2020.02.17., 15:00~15:40 - She expressed her desire to drink all types of cool and tangy carbonated juices through “decorating my own safe space,” while drawing a picture of herself drinking orange juice, grape juice, and strawberry carbonated juice. After drawing all things, she asked to draw her expression as happy in the paintings - The patient complained of abdominal pain with frequent vomiting through “feel my body (pain notation).” She also complained of low back pain while sitting a lot. She felt sleepy, but complained of difficulty sleeping due to pain and vomiting - Through the “My Day at the Hospital” session, she could not fall asleep until 12 am due to vomiting, but then repeatedly reported sleeping and sleeping, and continued to stay asleep until 6 am. She said she was doing nothing, despite all her efforts, even after she got up > Discussed the severity of the patient’s vomiting with the attending physician of the pediatric palliative care team and discussed it with the primary care team’s primary care practitioner
4th session	Date and time of meeting: 2020.02.20., 16:00~17:00 - Created a space outside the hospital where the cool wind blows through the “Magical Space” - She expressed her desire to become a doctor and treat herself by becoming a doctor later in the session “I became a captain.” She also expressed her desire to protect her family, her father, mother, her brother and grandmother anytime, anywhere - If there is a “mirror of truth,” in the session, she reported, “I want you to tell me why I keep getting sick” and “I want to ask you why I am still sick.” When asked what the mirror might say, she confirmed that she understood her medical situation, saying that she would be likely to answer, “I’m getting radiation therapy to be healthier.” Finally, she asked the truth mirror to help her get better soon - Confirmed the need for care. If treatment does not help anymore, “I think it will be very sad, but when that situation comes, death will come.” She specifically revealed her own wishes. She also expressed that she would like to sleep comfortably with her family without active treatment when the situation is approaching death. She says that she did not want to be alone, and wanted to be with her family as much as possible, and always asked for intentions before visiting herself - It was agreed that this content may be shared with medical staff. However, she feared that her mother would be sad and asked to keep it a secret from her

Table 5. Continued.

Session	Details
5th session	<p>Date and time of meeting: 2020.02.21., 11:00~11:30</p> <ul style="list-style-type: none"> <li>- Still vomiting and pain. The patient reported that the pain was so severe that there was not much to do.</li> <li>- Drew a clock for a day at home and a day at the hospital. At home, she said, "I start to sleep at 11 o'clock and sleep late until 9 o'clock. Play with my cell phone at 9~10, eat breakfast at 10~11, eat snacks, drinks, snacks, play with brother at 14~16, lunch and dinner at 16:00~17:00, and after 17:00, going for a walk outside at 19:00," before spending time playing with her cell phone from 19:00 to 23:00, and then waking up at hospital at 12 o'clock while sleeping. She got up and sat since 6 in the morning, but it was hard, so she didn't do anything</li> </ul> <p>&gt; After about 30 minutes of work, she expressed that she could not continue because it was too difficult.</p>
6th session	<p>Date and time of meeting: 2020.02.24., 15:00~16:00</p> <ul style="list-style-type: none"> <li>- Talked about "making my body sick when I'm in the hospital and making my body feel bad." Helping not to hurt grandma, TV, books (paper tubes), sister, dad, mom, cell phone, and water. The patient emphasized being thirsty</li> <li>&gt; She understood that she could not eat due to treatment, but she started crying because it was too hard to endure. Needed to provide the patient with emotional support</li> <li>- She reported that her illness made her heart feel "hard, scary, uneasy." Usually, the doctor explained her illness so that she can understand it</li> <li>- She responded to what she had been worried about since the fourth session. She would like the team to fully inform her about her medical condition, and she would like to know in advance if a bad situation would come because it would be more frightening to find out later. She gave her disease a nickname ("Bad disease!") expressing the desire to confuse it</li> <li>- Sharing good and hard memories. The patient expressed the present as the most difficult moment, and recently she often dreamed that the disease was not being cured, and at that time, she was especially afraid</li> <li>- She talked about "the way I dream of myself in the future." The patient drew a Chinese flag and imagined herself living in a large home in China a year later</li> <li>&gt; When sharing the contents of the consultation with the patient's parent, who was the main guardian, the patient asked the counselor to convey the patient's wishes to her parents, but for her parents to pretend that they did not know. The patient's mother asked the child to explain her wishes to the extent that she would not be in pain and agreed to inform the patient about her medical condition in the future.</li> <li>&gt; After sharing the consultation within the pediatric palliative care team, the team was requested to explain the medical condition to the patient in detail</li> </ul>
Could not proceed	<p>Date of visit: 2020.02.25.</p> <ul style="list-style-type: none"> <li>- Severe complaints of back pain. We decided to visit again the next day since consultation was not possible</li> </ul>
7th session	<p>Date and time of meeting: 2020.02.26., 11:00~11:40</p> <ul style="list-style-type: none"> <li>- Helped with emotions through interviews to imagine a pleasant tomorrow. She suddenly was able to leave the hospital, so she was happy to imagine a situation when she went home and ate coffee ice cream with her family, and the pain disappeared magically</li> <li>- She wrote a letter to her mother and decided when and how to deliver it</li> <li>&gt; After the end of the workbook, she flipped through from beginning to end and check the contents once again. She signed the last section and stamped her hand</li> </ul>

## DISCUSSION

This study was conducted to develop a workbook to facilitate the participation of child and adolescent patients who are receiving treatment for life-threatening diseases in communication about advance care planning and the decision-making process, as well as to present cases in which the workbook was

utilized to establish evidence of its clinical usefulness.

This study is significant in that a workbook was developed for the context of the South Korean medical field based on advance care planning workbooks for children and adolescents used abroad, and the quality of the workbook content was enhanced by creating separate versions for children and adolescents. It was found that the workbook could be utilized

according to the developers' intentions based on the instructions provided for the two versions at the beginning of the workbook. The importance of the counselor's role in helping the participant to speak about what he or she wanted was confirmed, which is in line with the importance of the counselor as a supporter suggested in international guidelines [13]. However, although international guidelines suggest that a child and adolescent expert should naturally bring up the workbook topics [16], due to the lack of child and adolescent experts in South Korea, a holistic approach not limited to certain occupations (i.e., involving doctors, nurses, social workers, and mental health therapists) is required. As such, workbook implementation instructions suitable for South Korea were suggested.

In the process of completing the workbook, the following six factors acted as facilitators. First, the counselor played a supportive role during the five to 10 sessions until the workbook was completed by adapting to the individual characteristics of the patients without placing limitations on age, the number of sessions, and the counseling format. Second, establishing trust with the participant was important; the main workbook counselor was a professional who had already established rapport with the participants, which helped facilitate appropriate communication when completing the workbook. Third, regarding topics that the patient wishes to avoid, the patient should be provided with opportunities to freely express his or her opinions without being forceful. Discussions about advance care planning, which is a sensitive topic, help to secure the patient's right to choose by confirming his or her level of understanding and preferences about their medical situation. Fourth, since the participants were minors, the counselor obtained consent from parents before using the workbook and defined the range of information-sharing and privacy protection after consulting with team members in the process of utilizing the workbook.

The counselor helped the patient understand himself or herself through the process of confirming and organizing what the participants wanted and desired to express clearly. Sixth, the counselor shared the content of the workbook by communicating with the main medical team while completing the workbook so that the discussions could be reflected in the treatment plans. In these cases, the workbook functioned as

a medium that enabled the provision of adequate end-of-life care by understanding the care and treatment format that patients themselves preferred through the choices patients made for care and for their future. Discussions about advance care planning with children and adolescents continue after the completion of the workbook, and it is difficult to standardize the number of workbook sessions and duration of discussions. However, it was confirmed that understanding the patient's wishes about care and treatment served as the foundation for subsequent discussions about advance care planning.

This workbook was developed so that it can be used regardless of the patient's specific disease or medical situation, and its expanded accessibility means that any patients receiving life-sustaining treatment can use it. Since the workbook participants inherently have frequently changing medical situations, counselors need to adjust the counseling format in a flexible manner to fit the patients' situations and should approach patients individually. The fact that the workbook helps children and adolescents to communicate in a healthy way by discussing advance care planning and expressing their own wishes in the treatment process is in line with the workbooks implemented abroad [25]. International studies emphasized the need to provide symptom management, which is the main role of the pediatric palliative care team, by closely communicating with the primary medical team [26]; this is consistent with the role of the workbook as a communication medium regarding the patient's symptoms in the present study. The patients in this study completed the workbook after they entered the end-of-life stage, but international reports have suggested that advance care planning discussions should take place in the beginning stages before the disease progresses and the patient enters the end-of-life stage [26], suggesting that it may be necessary to have patients complete the workbook earlier.

When composing the workbook, the sections of the international workbooks dealing with specific decision-making about funeral arrangements and grief management were deleted and replaced with topics of "creating a safe space", "using 'if' questions", "what I want", and "leaving a footprint" so that the topics of life and death could be handled indirectly. This revision is significant since it was based on considerations of the South Korean cultural setting, making this workbook distinctive from those developed in other nations. Death is a topic

that is often avoided due to the uncertainty of the prognosis and the negative perceptions of patients and caretakers [27], but it is meaningful for child and adolescent patients to have the freedom to express their own values about life and death through completing the workbook. Lastly, the results of this study suggest necessary considerations and behavioral guidelines for using the workbook and can be used as foundational data at children's hospitals or other institutions that require discussions about advance care planning with children and adolescents.

The limitations of this study and suggestions for future research are as follows. First, the advance care planning workbook was developed at the same time that it was utilized by specific patients, and there is currently only a small number of case studies on discussions about advance care planning with children and adolescents. Therefore, studies about this issue should continue to be conducted. Future studies should investigate difficulties that were encountered in the process of utilizing the workbook and revise its content accordingly. However, it is significant that this study was the first to develop an advance care planning workbook for children and adolescents and to suggest case applications in South Korea, and that this study proposed guidelines for advance care planning among children and adolescents.

Second, this was a retrospective study that extracted data from participants' medical records limited to the time when they used the advance care planning workbook. It had a limited ability to determine whether completion of the workbook had any influence on the patients and family members at the time of treatment or after the patients' death. It will be meaningful to track the effect of using the workbook and the persistence of its effect after the patients' death among the family members of patients who had discussions through the advance care planning workbook.

Lastly, it is suggested that subsequent studies should examine

the need for discussions about advance care planning among child and adolescent palliative care patients and their family members. Furthermore, future research should survey all institutions that actually use the workbook to understand the circumstances of its implementation.

## CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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## SUPPLEMENTARY MATERIALS

Supplementary materials can be found via <https://doi.org/10.14475/kjhpc.2020.23.4.212>.

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