pISSN 2765-3072 • eISSN 2765-3080

# Volunteer Experiences of Pediatric Palliative Care among University Students: A Phenomenological Approach

Yi Ji Moon, M.S.W., Ph.D., Candidate\*,†

\*Department of Social Welfare, Sungkyunkwan University,

†Integrative Care Hub, Seoul National University Children's Hospital, Seoul, Korea

**Purpose:** This phenomenological analysis was conducted to explore the experiences of college student volunteers in the field of pediatric palliative care. **Methods:** In-depth interviews were conducted with nine study participants who had experience volunteering with children receiving pediatric palliative care. The study analysis was conducted using the Colaizzi method, a rigorous qualitative research method, to develop "intra-group" comparisons among the study participants. **Results:** Through an analysis of the data, 51 themes, 18 theme clusters, and five main categories were derived. The results confirmed that the experience of university student volunteers in pediatric palliative care can be summarized as "awareness of the role of a volunteer," "difficulties encountered while volunteering," "efforts to overcome the difficulties of volunteer work," "personal reflection," and "awareness of life and death." **Conclusion:** The results of this study can be used as a practical guide for the effective management of volunteers in the pediatric palliative care setting.

Received June 29, 2022 Revised August 16, 2022 Accepted August 17, 2022

Correspondence to

Yi Ji Moon ORCID:

https://orcid.org/0000-0003-3946-2205 E-mail: moonviii@gmail.com

Key Words: Pediatrics, Palliative care, Hospice care, Volunteers

# **INTRODUCTION**

#### 1. Background

Ongoing pilot projects in pediatric palliative care have been in place at 10 institutions in Korea since 2018 [1]. However, there are still a variety of difficulties in appropriately providing pediatric palliative care services [2,3]. Pediatric palliative care involves the collaboration of interdisciplinary team members, including physicians, nurses, social workers, art therapists, spiritual interventionists, and volunteers, who provide fundamental services [4]. In the collaborative field of pediatric palliative care, volunteers spend one—on—one time with pediatric patients and their families, allowing them to express any anxiety and depression they may be experiencing [5]. In addition

to this direct service, they also provide indirect services, such as assisting with the office work that supports medical treatments, providing clinical treatment support, and participating in fundraising activities [6]. Volunteers also provide diverse support roles including help with housekeeping, gardening, education, reading activities, play activities, age—appropriate games, outings, caring for siblings, and support during special events [7].

Pediatric palliative care volunteers are likely to feel stress due to the complicated psychological burdens and the variety of challenges they are frequently exposed to, including experiences of bereavement with the loss of pediatric patients [4,8]. Although older adult hospice volunteers have typically learned to continue with their duties while simultaneously attending to their own existential well-being, despite experiencing

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (http://creativecommons.org/licenses/by-nc/4.0/) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.



loss [9,10], university student volunteers may not be used to managing such experiences of loss. However, they share the characteristic of all volunteers in that they find meaning in voluntary service because the activities satisfy their personal values and serve as a foundation for self-development [11]. In a study that analyzed the motivations of volunteers working in the field of palliative care, the group aged 20~39 years were satisfied with external factors such as personal careerpath benefits, compatibility with their lifestyle, and compensation from the community; while the group aged 60 years and above were satisfied with internal factors such as friendship with patients, life values, pride in the work, and the opportunity to study death [12].

According to international studies, the factors needed to address the sense of loss experienced by volunteers in the field of pediatric palliative care are: 1) basic education related to pediatric palliative care with detailed explanations of the field and roles of the volunteer to enhance their understanding [13,14] and 2) meaningful feedback including active communication with employees, acknowledgement of the value of volunteer activities, and respect for volunteers to help them find the meaning of positive life [15]. However, there are few Korean studies on volunteer activities in the field of pediatric palliative care. Although the impact of education for hospice volunteers has been investigated [13,14], it was limited to adult hospice care, and the characteristics of volunteer activities in pediatric palliative care were not discussed. Pilot projects in pediatric palliative care have only recently started in Korea, and only limited data has been accumulated. Although the characteristics of hospice volunteers and the meaning of their experiences working with hospice patients have been studied in-depth, as well as the effects of volunteering on university students [12,15], these studies were conducted in an adult hospice environment. The experience of university student volunteers in the field of pediatric palliative care has not been analyzed. The role of pediatric palliative care volunteers has been described in some international studies [7,16] but the type of pediatric palliative care services provided varied by country, depending on each country's health-care system. It is difficult to apply the examples from foreign countries to Korean pediatric palliative care services due to the cultural, environmental, and systematic differences.

Currently, the proportion of university students in the group of pediatric palliative care volunteers in Korea is high to help minimize the age gap between pediatric patients and volunteers, increase approachability, and enhance the effect of mentoring. However, few studies have considered the environmental characteristics of the field of pediatric palliative care. Therefore, this empirical study aimed to analyze the experiences of university student volunteers working with pediatric patients and their families in Korea and suggest future directions of volunteer management in pediatric palliative care.

#### 2. Purpose

Based on university students' volunteer experiences in pediatric palliative care, this study aimed to provide basic data for the development of future care projects and derive practical suggestions.

### **METHODS**

#### 1. Study design

This qualitative study applied Colaizzi's analysis method [17]. The seven-step rigorous analysis described by Colaizzi was considered appropriate to investigate the new themes and relationships in this study, by analyzing previously unconfirmed phenomena and investigating experiences via face-to-face interviews and activity logs.

#### 2. Participants

The participants in this study were university students who had participated in a one-on-one mentoring program (in the pediatric palliative care field) at a university hospital in Seoul, Korea. This was a children's hospital with 250 beds that recruited and operated a university student volunteer group for hospital-based pediatric palliative care. The participants were selected using purposive sampling. The hospital had been selected for a pediatric palliative care pilot project by the Ministry of Welfare in July 2018, continued to operate the project through 2022, and also provided consulting services. Each university student volunteer supported a designated pediatric patient for 1~2 hours once a week by reading books, supporting their learning, and providing play activities tailored to the



pediatric patient's individual needs [18].

The selection criteria for participants were set to determine sufficient volunteering experience and an understanding of the meaning of volunteering in pediatric palliative care. The criteria included those who: 1) had volunteered for two seasons or more (1 year or longer) and demonstrated a sufficient understanding of volunteer work in pediatric palliative care. 2) had regularly met with one pediatric patient for five sessions or more, and 3) had experienced bereavement due to the loss of a pediatric patient. The exclusion criterion was student volunteers who had experienced bereavement due to the loss of a pediatric patient within the last 3 months, based on the five stages of grief suggested by Kubler-Ross and Kessler [19]. At the time of data collection, 37 of the total 782 members of the pediatric palliative care volunteer group met the selection criteria. Two members were excluded who had been highly exposed to loss and depression. Thus, 35 members voluntarily consented to participate in the study and signed a written consent form after the purpose of the study was explained. However, 26 members did not follow up, leaving a total of nine participants in the study.

#### 3. Data collection

This study was approved by the institutional review board (IRB FILE No. SKKU 2019-11-027) of the university. The researcher explained the study purpose, time period of the study, methods, possible benefits and losses, confidentiality, and the voluntary participation to each participant and provided a copy of their written consent form. After the interview was completed, a small reward was provided. To secure the ethics of the research, integrity in conducting the research was maintained and the ethical regulations in the relevant research field were followed. The data were collected from December 2019 to March 2020. One-on-one interviews were conducted for 60 minutes per session, with seven participants interviewed once and two participants interviewed twice. By conducting a pilot interview with two participants, the semi-structured interview questions were developed to examine the experiences of volunteers in pediatric palliative care. The interview questionnaire was revised and supplemented, referencing questions suggested by Muckaden and Pandya [20]. The specific questions were: 1) "What inspired you to begin volunteering?", 2)

"What are some memorable experiences during your time as a volunteer?", 3) "Did you have any difficulties during your time as a volunteer?", and 4) "What was your primary role as a volunteer?" The questions exploring the meaning of volunteering in pediatric palliative care in an individual's life were: 1) "What part does being a volunteer occupy in your life?", 2) "Did you think about your life during your time as a volunteer?", and 3) "Did you think about your primary life values as they applied to your work as a volunteer?" The interview was conducted in a conference room inside or outside the hospital, depending on the interviewee's preference. The researcher was also an interviewer and had worked as a dedicated social worker in the university hospital's pediatric palliative care department since January 2014 to gain an understanding of the pediatric palliative care field. Before working at the hospital, the researcher completed the End-of-life Nursing Education Consortium Pediatric Palliative Care program to enhance a theoretical understanding of the field, obtained an educator certificate in Education in Palliative and End-of-life Care Pediatrics, and received a master's degree with a thesis on pediatric palliative care using qualitative research.

#### 4. Data analysis

The data were analyzed to identify common themes using the seven-step analysis suggested by Colaizzi [17] including: 1) reading participants' statements several times to become familiarized with the statement, 2) identifying and extracting important themes from the statements, 3) grouping meaningful themes and constructing categories, 4) developing a detailed description, 5) creating a basic structure, and 6) identifying, and 7) verifying the basic structure. The Colaizzi analysis method [17] focuses on determining the common characteristics of all participants. The recorded interviews were transcribed and converted to raw data. The transcriptions were read several times, then categorized with keywords for each theme, and with semantic units for analyzed raw data and categorized data. By confirming the related content in the data, the meanings contained in the data were identified, summarized, and classified into meaningful units. In the analysis process, the categories were reclassified, revised, and supplemented by naming them as more meaningful categories.



#### 5. Rigor

To increase the rigor of the study, Padgett's strategies (i.e., advice from peer groups, reconfirmation by study participants, and maintaining data for an audit) were used [21]. The participants' emotional changes and their expressions regarding the meaning of volunteering were identified by securing the participants' activity logs. To ensure the consistency and credibility of coding in the content analysis, the statements were sent back to the participants after content analysis, and semantic consistency was confirmed through participant reconfirmation and/or revision. Subsequently, data triangulation was performed to elaborate on the data interpretation by requesting review by a doctoral major in social welfare who had previously conducted qualitative research.

### **RESULTS**

#### 1. General characteristics of participants

Table 1 describes the general characteristics of the participants and their experience volunteering in pediatric palliative care. Eight out of nine participants were women, and the mean age was 25.44 years. All participants were unmarried and were current university students or seeking a job. The average volunteer period was 2 years, and all participants were long-term volunteers with at least 1.5 years of experience.

#### 2. Analysis results

To understand the meaning of volunteering in pediatric pal-

**Table 1.** Characteristics of Participants.

Category	Sex	Age (yr)	Volunteer time	University major
А	Female	27	2.0 years	English interpretation and translation
В	Female	26	2.0 years	Management
С	Male	29	1.5 years	Management
D	Female	27	1.5 years	Basic medicine
Е	Female	23	2.0 years	Rehabilitation
F	Female	24	2.5 years	Content design
G	Female	26	2.0 years	Social welfare
Н	Female	23	2.0 years	Social welfare
	Female	24	3.0 years	Education

liative care, text and theme statements were identified and analyzed. A total of 51 meaningful theme statements, 18 theme clusters, and five categories were derived (Table 2).

#### 1) Awareness of the role of a volunteer

#### (1) Sharing from the heart

The participants used the terms "sharing from the heart," "sincerity," and "friends" rather than "volunteering" and described the major role of a volunteer as "sharing from the heart with pediatric patients" and "working with an attitude of sincerity."

"I think it is particularly important to share from the heart here, unlike other administrative types of volunteer work" (Participant D).

"If I approach children with sincerity, they will have more fun during the visits from volunteers" (Participant G).

"I feel like I want to be with them as a friend, in a place where they might feel lonely" (Participant H).

#### (2) Rapport with patients and parents

The participants described the meaning and the primary role of volunteering as "standing in to do tasks when the parents cannot do them and providing relief and rest to the primary caregiver during difficult treatment and care situations."

"Since the pediatric intensive care unit allows only a limited time for parents to see their children, I convey to the parents what we did and what we talked about" (Participant C).

"Even if it was short, I was able to provide time for the parents to have a short break" (Participant F).

In addition, participants felt that the formation of rapport was an important part of the volunteers' role in helping pediatric patients who spent their days in a limited space (a hospital room) and only indirectly experienced the outside world. They attempted to fill the pediatric patients' lives in the hospital with pleasant moments.



Table 2. Framework and Categorization for Analysis of the Experience of University Student Volunteers in Pediatric Palliative Care.

	lable 2. Framework and Cal	l <b>able 2.</b> Hamework and Categorization for Analysis of the Experience of University Student, volunteers in Pediatric Pallauve Care.
Category	Theme cluster	Meaningful theme
Awareness of the role of a volunteer	Sharing from the heart	<ol> <li>"I think it is particularly important to share from the heart here, unlike other administrative types of volunteer work."</li> <li>"If I approach children with sincerity, they will have more fun during the visits from volunteers."</li> <li>"I feel like I want to be with them as a friend, in a place where they might feel lonely."</li> </ol>
	Rapport with patients and parents	<ol> <li>Since the pediatric intensive care unit allows only a limited time for parents to see their children, I convey to the parents what we did and what we talked about."</li> <li>Even if it was short, I was able to provide time for the parents to have a short break."</li> <li>At first. I thought that they were tired from the scary treatment environment, but then I saw that playing with IIs was precious time.</li> </ol>
		a time for the children to really refresh."  7) "As volunteers who come to see the children, we can be a window of communication with the outside world."
	Continuity of the volunteer role	8) "I work with the thought that I am a witness to beautiful moments in this child's life." 9) "I wrote this with sincerity hoping that it can be a comfort for the bereaved parents who may receive it."
Difficulties encountered while volunteering	Fear of new fields	<ul> <li>10) "Can I really do well? Can I do this even if I am not in a related major? I worried about these things."</li> <li>11) "Since I had not been given information, I was a little worried about becoming infected."</li> <li>12) "It was my first time visiting the intensive care unit, and I thought "Is reading a book really helpful?"</li> <li>13) "I worry when the machine alarms or something goes wrong because I don't know what to do."</li> <li>14) "There were so many lines that I felt that I should bay more attention."</li> </ul>
	Difficulty in coping with pediatric patients and their families	<ol> <li>I worried a lot whether my words or actions would furt them instead."</li> <li>"When I experience a setback. I get stressed thinking that I must have done something wrong."</li> <li>"On the days when chemotherapy was finished, the child was exhausted. So, it was hard when there was nothing I could do."</li> <li>"I don't know how to approach older children. They don't respond even if I talk to them."</li> </ol>
	Experiencing bereavement	19) "After the parting, it (the emotion) kept going. I sometimes dreamed too, it was the most difficult time as a volunteer." 20) "I think I needed some time alone to pull myself together."



$\overline{}$	ż
~	٠
Œ	J
_	3
₪	_
	1
7	=
~	-
$\sim$	٦
C	5
_	1
0	i
٥	2
2	5
π.	3
-	-

Effective training before starting to overcome the difficulties work rolunteer of volunteer work a Resolving difficulties through communication with team members and volunteer section guestions through registry and volunteer section during a volunteer section guestion strong a volunteer section during a volunteer section during a volunteer section guestion strong by a volunteer section guestion strong by a volunteer section of the section guestion strong by a volunteer section of the section guestion strong by a volunteer section of the section guestion of the section of the section guestion of the section of the section guestion of the section guestion of the section of t			lable 2. On lattice.
Effective training before starting to volunteer Resolving difficulties through communication with team members Resolving questions through regular feedback from managers Receiving education during a volunteer session Strengthening the meaning of volunteering by experiencing change Responsibility in the volunteer role Responsibility in the volunteer role Nolunteers' reflection on their own lives Discovering a life-values compass  Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being	Category	Theme cluster	Meaningful theme
Resolving difficulties through communication with team members Resolving questions through regular feedback from managers Receiving education during a volunteer session Strengthening the meaning of volunteering by experiencing change Responsibility in the volunteer role Responsibility in the volunteer role Nolunteers' reflection on their own lives Discovering a life-values compass  Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being	Efforts to	Effective training before starting to	21) "During the orientation training. I thought, 'Although this is not my major area of study, I can do it if I have this level of education."
communication with team members Resolving questions through regular feedback from managers Receiving education during a volunteer session Strengthening the meaning of volunteering by experiencing change Responsibility in the volunteer role Responsibility in the volunteer role Responsibility in the solunteer role Discovering a life-values compass  Peflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being	overcome the difficulties of volunteer work	volunteer Resolving difficulties through	<ul><li>2.2) Inly anxiety was relieved when it was explained to me how to deal with it.</li><li>23) "We learned a lot from each other by sharing how we communicated with the children."</li></ul>
Resolving questions through regular feedback from managers Receiving education during a volunteer session Strengthening the meaning of volunteering by experiencing change Responsibility in the volunteer role Responsibility in the volunteer role Discovering a life-values compass  Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death  The importance of time and being		communication with	24) "I think that active communication is necessary for volunteering. I highly recommend promoting team meetings."
regular feedback from managers Receiving education during a volunteer session Strengthening the meaning of volunteering by experiencing change Responsibility in the volunteer role Responsibility in the volunteer role Discovering a life-values compass  Peflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		team members Decolving on jestions through	. 25) In elopportunity to receive recondar from the team during the week was helpful. 26) "If thore are unsolved iscuss it is assential to request a more litation emastricely and receive advice immediately."
Receiving education during a volunteer session Strengthening the meaning of volunteering by experiencing change Responsibility in the volunteer role Responsibility in the volunteer role Discovering a life-values compass  Reflection on interpersonal relationships Interpersonal relationships Interperson in the study of death Changes in the perception of death The importance of time and being		resolving questions unough regular feedback from managers	20) If there are ut issued, it is essential to request a consultation production are technelatively. 27) "I appreciated receiving feedback: it made me think about the things that I should improve upon."
a volunteer session Strengthening the meaning of volunteering by experiencing change Responsibility in the volunteer role Volunteers' reflection on their own lives Discovering a life-values compass Reflection on interpersonal relationships Interpersonal relationships Changes in the study of death Changes in the perception of death		Receiving education during	28) "It would help to teach us playing skills or specific educational play methods during the volunteer session, while we were with the children."
Strengthening the meaning of volunteering by experiencing change Responsibility in the volunteer role Volunteers' reflection on their own lives Discovering a life-values compass Reflection on interpersonal relationships Interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		a volunteer session	
volunteering by experiencing change Responsibility in the volunteer role Volunteers' reflection on their own lives Discovering a life-values compass Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		Strengthening the meaning of	29) "At some point, the child told his/her story. It was thrilling and surprising."
experiencing change Responsibility in the volunteer role Volunteers' reflection on their own lives Discovering a life-values compass Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		volunteering by	30) "I was proud that the child's mom said, 'thank you' with a brighter face after taking a break."
Responsibility in the volunteer role Volunteers' reflection on their own lives Discovering a life-values compass Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		experiericing charige	
Volunteers' reflection on their own lives Discovering a life-values compass Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being	Personal reflections	Responsibility in the volunteer role	31) "I felt a responsibility to the child."
Volunteers' reflection on their own lives  Discovering a life-values compass  Reflection on interpersonal relationships  Interest in the study of death  Changes in the perception of death  The importance of time and being			32) "I wanted to give the child more abundant experiences in a limited time and space."
Volunteers' reflection on their own lives  Discovering a life-values compass  Reflection on interpersonal relationships  Interest in the study of death  Changes in the perception of death  The importance of time and being			3.5) Heit that we were working togerner, that I was a member of the pediatric palliative care team.
their own lives Discovering a life-values compass Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		Volunteers' reflection on	34) "I felt my daily life was precious and was grateful. Volunteering made me look back on the life that I had previously complained about."
Discovering a life-values compass Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		their own lives	35) "My views on the value of life changed. I can now find understanding, respect, and love in each situation."
Discovering a life-values compass Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being			36) "Might it be the weight of the soul? I thought that I should endeavor to value quality instead of quantity."
Discovering a life-values compass Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being			37) "I have been very strict with myself, but I can be more generous with myself now."
Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		Discovering a life-values compass	38) "Volunteering was like a compass. It was an opportunity to decide the direction that I was going to go."
Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being			39) "Volunteering helped me discover what I like and identify my dreams."
Reflection on interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being			40) "My interest in people with disabilities grew."
interpersonal relationships Interest in the study of death Changes in the perception of death The importance of time and being		Reflection on	41) "I learned to keep a reasonable distance psychologically."
Interest in the study of death Changes in the perception of death The importance of time and being		interpersonal relationships	42) "I thought that I should do my best for the people around me."
Interest in the study of death Changes in the perception of death The importance of time and being			43) "I spent more time with my family."
	Awareness of life and death	Interest in the study of death	44) "I read a few books on it and thought about life and death."
			45) "I began living with gratitude for every day and was grateful for my given circumstances."
		Changes in the perception of death	46) "While volunteering, I learned to think about what happens after the death, the people left behind and the families."
			47) "I think that my thoughts on death changed to a positive feeling."
			48) "I thought that I could consider the idea of a happy death."
50) "I hope that there was no wasted		The importance of time and being	49) "I thought that the time I last met with the child was very precious."
51) "Want to use time more usefully			50) "I hope that there was no wasted time."
			51) "I want to use time more usefully."



"At first, I thought that they were tired from the scary treatment environment, but then I saw that playing with us was precious time, a time for the children to really refresh" (Participant B).

"As volunteers who come to see the children, we can be a window of communication with the outside world" (Participant H).

#### (3) Continuity of the volunteer role

The participants used the terms "memory" and "witness" and valued the continuity of their role as a volunteer, that it was ongoing and not limited to one point in time.

"I work with the thought that I am a witness to beautiful moments in this child's life" (Participant A).

"I wrote this with sincerity hoping that it can be a comfort for the bereaved parents who may receive it" (Participant E).

#### 2) Difficulties encountered while volunteering

#### (1) Fear of new fields

The participants experienced feelings of unfamiliarity and fear of seeming ignorant as they first encountered pediatric patients being treated for severe diseases and receiving pediatric palliative care.

"'Can I really do well? Can I do this even if I am not in a related major?' I worried about these things" (Participant C).

"Since I had not been given information, I was a little worried about becoming infected" (Participant I).

The participants frequently expressed anxiety about working as a non-specialist, even after having begun their volunteer work. They initially experienced confusion and uncertainty about their role in meeting the needs of pediatric patients being treated for severe and rare incurable diseases.

"It was my first time visiting the intensive care unit, and I thought 'Is reading a book really helpful?'" (Participant I).

"I worry when the machine alarms or something goes wrong because I don't know what to do" (Participant D).

"There were so many lines that I felt that I should pay more attention" (Participant F).

# (2) Difficulty in coping with pediatric patients and their

The participants used the words "mistake," "tension," and "concern" to describe their difficulties coping with pediatric patients and their families who were experiencing complex physical, psychological, and social problems due to the uncertainty of the children's medical conditions.

"I worried a lot whether my words or actions would hurt them instead" (Participant G).

Moreover, when volunteering was put on hold due to uncontrolled medical conditions, the participants felt "incompetent" or that it was "their fault" and experienced a decrease in self-efficacy.

"When I experience a setback, I get stressed thinking that I must have done something wrong" (Participant A).

"On the days when chemotherapy was finished, the child was exhausted. So, it was hard when there was nothing I could do" (Participant B).

"I don't know how to approach older children. They don't respond even if I talk to them" (Participant D).

#### (3) Experiencing bereavement

When participants encountered news of the death of a pediatric patient whom they had been visiting regularly, they described it as emotionally difficult to deal with. The participants who had direct relationships with pediatric patients who died experienced loss and sadness, moving through the process of denial, finding it "hard to believe or hard to accept." Even after time passed, they expressed continuing psychological difficulties and the need to deal with loss and mourning.



"After the parting, it (the emotion) kept going. I sometimes dreamed too. It was the most difficult time as a volunteer" (Participant C).

"I think I needed some time alone to pull myself together" (Participant F).

#### 3) Efforts to overcome the difficulties of volunteer work

#### (1) Effective training before starting to volunteer

It was confirmed that advance training helped reduce the anxiety of participants and enhanced their confidence in the unfamiliar field of pediatric palliative care.

"During the orientation training, I thought, 'Although this is not my major area of study, I can do it if I have this level of education'" (Participant A).

"My anxiety was relieved when it was explained to me how to deal with it" (Participant E).

# (2) Resolving difficulties through communication with team members

The participants communicated naturally with other volunteers who had the same experiences. As a team, they grew close and were a great help to each other in overcoming the difficulties of volunteering.

"We learned a lot from each other by sharing how we communicated with the children" (Participant B).

"I think that active communication is necessary for volunteering. I highly recommend promoting team meetings" (Participant A).

"The opportunity to receive feedback from the team during the week was helpful" (Participant I).

#### (3) Resolving questions through regular feedback from managers

Immediately after a volunteer session, the participants often sought advice about difficult issues. Through developmental feedback, they gathered knowledge and enhanced their self-confidence.

"If there are unsolved issues, it is essential to request a consultation proactively and receive advice immediately" (Participant A).

"I appreciated receiving feedback; it made me think about the things that I should improve upon" (Participant E).

#### (4) Receiving education during a volunteer session

Education and feedback in the middle of volunteering helped participants to review the overall session, and to think about making the time remaining in the session more useful.

"It would help to teach us playing skills or specific educational play methods during the volunteer session, while we were with the children" (Participant C).

# (5) Strengthening the meaning of volunteering by experiencing change

The participants appreciated the rewards of providing positive effort and then experiencing the changes those efforts brought to the lives of the pediatric patients and their families. This positive experience reinforced the meaning of being a volunteer and encouraged them to continue volunteering.

"At some point, the child told his/her story. It was thrilling and surprising" (Participant G).

"I was proud that the child's mom said, 'thank you' with a brighter face after taking a break" (Participant B).

#### 4) Personal reflections

#### (1) Responsibility in the volunteer role

Encountering pediatric patients who looked forward to their weekly time with the volunteers, the participants felt the importance of their role as a member of the pediatric palliative care team and took it seriously. In addition, they showed a willingness to mature and learn, to become a good influence on the pediatric patients.

"I felt a responsibility to the child" (Participant G).

"I wanted to give the child more abundant experiences in a



limited time and space" (Participant C).

"I felt that we were working together, that I was a member of the pediatric palliative care team" (Participant I).

#### (2) Volunteers' reflection on their own lives

The volunteer experience was an opportunity for the participants to look back on their lives and to change attitudes and thoughts about life. It strengthened their ability to reflect and think deeply about their own lives.

"I felt my daily life was precious and was grateful. Volunteering made me look back on the life that I had previously complained about" (Participant F).

"My views on the value of life changed. I can now find understanding, respect, and love in each situation" (Participant G).

"Might it be the weight of the soul? I thought that I should endeavor to value quality instead of quantity" (Participant E).

"I have been very strict with myself, but I can be more generous with myself now" (Participant D).

#### (3) Discovering a life-values compass

The participants did not stop looking back on their lives; instead, they reflected upon changes for the future. Volunteering helped the participants to focus the direction of their lives and realize their dreams.

"Volunteering was like a compass. It was an opportunity to decide the direction that I was going to go" (Participant A).

"Volunteering helped me discover what I like and identify my dreams" (Participant I).

"My interest in people with disabilities grew" (Participant G).

#### (4) Reflection on interpersonal relationships

Beyond self-discovery, the participants reported a maturing of interpersonal relationships in which they took care of themselves and others in a balanced way. This experience changed views about their relationships with others.

"I learned to keep a reasonable distance psychologically" (Participant A).

"I thought that I should do my best for the people around me" (Participant B).

"I spent more time with my family" (Participant G).

#### 5) Awareness of life and death

#### (1) Interest in the study of death

As volunteers experiencing bereavement and the loss of a pediatric patient, the participants expanded their way of thinking about life and death by various methods such as reading related books or watching videos.

"I read a few books on it and thought about life and death" (Participant E).

"I began living with gratitude for every day and was grateful for my given circumstances" (Participant F).

#### (2) Changes in the perception of death

Some participants' perceptions of death before volunteering expanded to include the concept of a happy death and to consider the situation of the people left behind after a death. They learned to value the role of volunteers.

"While volunteering, I learned to think about what happens after the death, the people left behind and the families" (Participant A).

"I think that my thoughts on death changed to a positive feeling" (Participant D).

"I thought that I could consider the idea of a happy death" (Participant G).

#### (3) The importance of time and being

The perceptions of life and death led to insights on the meaning of time and being. The participants perceived the pre-



ciousness of each moment (that could be the last) and learned to appreciate the importance of spending time meaningfully. This was shown by the use of expressions such as "preciousness of time," "hope not to waste time," and "useful time."

"I thought that the time I last met with the child was very precious" (Participant H).

"I hope that there was no wasted time" (Participant C).

"I want to use time more usefully" (Participant E).

### DISCUSSION

This study conducted in-depth interviews to identify specific volunteer problem areas, to better manage the development of volunteer programs in pediatric palliative care. This phenomenological study assessed the rewards and difficulties for university student volunteers in the pediatric palliative care field in Korea, where related research was rare. This study is meaningful in that it presents foundational data for a support plan for managing volunteers effectively in the pediatric palliative care field in Korea, where this service is relatively new.

In this study, the university student volunteers perceived that sharing from the heart, forming rapport, and continuity of support were the roles of volunteers. They described fear of an unfamiliar field of study, difficulty in coping, and the experience of bereavement as the difficult aspects of volunteering. It was confirmed that these difficulties were overcome through effective pre-training, communication with team members, regular feedback from managers, reviewing experiences with other volunteers, and noticing positive changes in the pediatric patients and their families. Moreover, volunteering contributed to the maturation of volunteers through the responsibility of the role, reflections on life, setting life values, and reflections on interpersonal relationships. The participants also expanded their understanding of life and death by experiencing changes in their previous perceptions of death, studying and pursuing their natural interest in death, and discovering what time and being meant to them. These results are consistent with previous studies [7,16], which reported that providing opportunities for volunteers to experience a sense of achievement, self-reflection,

and positive rewards helped to promote volunteer participation. Claxton [8] suggested that, to overcome volunteers' stress due to the inherent loss experienced in palliative care, practical management methods should be incorporated, such as setting clear boundaries in the volunteers' role, providing education on possible ethical issues and on the death process, and roleplaying difficult situations to enhance coping strategies.

The participants in this study experienced life and death while volunteering. They explored the problems they experienced by referring to related books or searching the internet, which then led to self-reflection and concern for others. Roessler et al. [12] suggested that university student volunteers were more satisfied with the volunteer experience than older volunteers due to the satisfaction derived from external factors such as personal interests and goals. In addition to satisfaction from external factors, the participants in this study also derived satisfaction from internal factors such as life values, bonds with pediatric patients, and the exploration of death.

To improve pediatric palliative care volunteers' understanding of an unfamiliar area, this study suggests the need for systematic educational content to include disease information, examples of volunteer experiences, and the procedures for care after death. Further research on composing educational guidelines for volunteers in pediatric palliative care and preparing unified education guidelines for each institution is suggested. Meyer et al. [13] reported on the need for effective communication by identifying the type of information that volunteers in pediatric palliative care wanted to receive. Based on the results of a previous study as well as this study, providing education and cooperative communication between volunteers and managers is crucial. Since university students volunteer while also attending university, are generally unmarried, and have a limited period of time for volunteering when compared to older volunteers, it is suggested that volunteer programs be organized to reflect those characteristics.

Second, this study suggests that regular communication was necessary for volunteers to solve the various difficulties they encountered while volunteering and that volunteers be taught appropriate performance skills. According to a study of adult Korean volunteers, respect from medical staff and support from peer volunteers were found to be key factors for volunteers [10]. This study also found that cooperation from peer



volunteers was significant, and confirmed that regular feedback from managers was necessary to solve difficulties in the field. Compared to a previous study on proficient volunteers (adults with an average of 10 years' experience) [10], the current study results were based on volunteers with different experience and proficiency levels. The history of pediatric palliative care is relatively short and the longest volunteer experience was only 3 years. A previous international study [14] recommended increasing volunteer satisfaction by providing benefits and feedback to strengthen the motivation to continue volunteering in the pediatric palliative care field. Based on these results, a systematic two-way communication system could be established to provide a venue for volunteers to review their activities.

Third, the loss and psychological difficulties of bereavement, as experienced by the volunteers in this study, suggest the need to develop programs that support volunteers' ability to cope with loss as well as preparing plans that strengthen the psychological support capacity in Korean hospitals with pediatric palliative care programs. Older adult volunteers, often motivated by a spirituality based on the wisdom of life and religion, do not express great difficulty in meeting people who are about to die [10]. However, it is more difficult for university student volunteers to experience bereavement and loss compared to older adult volunteers since they are less likely to have experienced death, and often lack the skills to communicate with caregivers older than themselves. Since volunteers in the pediatric palliative care field experience death and loss during their work, a support system to prevent psychological exhaustion should be reinforced with volunteer group gatherings to share personal concerns. It is important to provide opportunities for volunteers to reflect on the meaning of life and death because it fosters a healthy perception of death [11].

Pediatric palliative care volunteers need to experience external rewards (e.g., a path to career goals, a sense of belonging, and respect from the community) and internal rewards (e.g., relationships with pediatric patients, exploration of life and death, and pride in volunteering) to increase satisfaction and enhance their work. A previous study on the experiences of hospice/palliative care volunteers also included the rewards: 1) respect from the palliative care staff and the medical staff, 2) a sense of belonging, and 3) the discovery of a matured self through self-reflection [10]. The current study also confirmed that specific feedback on volunteers' performance, as well as communication with team members, was necessary. Volunteer programs operate most effectively when they offer opportunities such as exhaustion prevention programs and training sessions with pediatric palliative care professionals, which provide volunteers with a sense of belonging and promote motivation.

Finally, the major limitation of this study was that the participants were recruited from pediatric palliative care volunteers in a single hospital and the results may not be generalizable to all of Korea. As the pilot project continues, further research that includes volunteers from every institution in the pilot project will make it possible to investigate the overall status of volunteer management in the pediatric palliative care field and to conduct a comparative analysis of operation methods according to the characteristics of each institution.

# **CONFLICT OF INTEREST**

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

# **ORCID**

Yi Ji Moon, https://orcid.org/0000-0003-3946-2205

# SUPPLEMENTARY MATERIALS

Supplementary materials can be found via https://doi. org/10.14475/jhpc.2022.25.3.121.

## **REFERENCES**

1. Distribution of information on pediatric palliative care [Internet]. Goyang: National Hospice Center; 2021 [cited 2022 Feb 22]. Available from: https://www.hospice.go.kr/pain/archivesView.do? brd\_no=101059.



- 2. Moon YJ, Shin HY, Kim MS, Song IG, Kim CH, Yu J, et al. Palliative care practitioners' perception toward pediatric palliative care in the Republic of Korea, Korean J Hosp Palliat Care 2019;22:39-47.
- 3. Yu J, Song IG, Kim CH, Moon YJ, Shin HY, Kim MS. Perceptions of pediatric palliative care among physicians who care for pediatric patients in South Korea, J Palliat Med 2020;23:346-52.
- 4. Azuero CB, Harris GM, Allen RS, Williams BR, Kvale E, Ritchie CS. Team-based volunteerism with the seriously ill: a qualitative analysis from 10 volunteers' perspectives. J Soc Work End Life Palliat Care 2014;10:282-95.
- 5. Claxton-Oldfield S. Hospice palliative care volunteers: the benefits for patients, family caregivers, and the volunteers. Palliat Support Care 2015;13:809-13.
- 6. NHPCO's facts and figures: hospice care in America [Internet]. Virginia: National Hospice and Palliative Care Organization; 2021 [cited 2022] Mar 1]. Available from: https://-figures-report-shows-changes-in-hospice-patient-diagnoses.
- 7. Duggal S, Farah P, Straatman LP, Freeman L, Dickson S. The volunteer program in a Children's Hospice. J Palliat Med 2008;11:997-1001.
- 8. Claxton-Oldfield S. Hospice palliative care volunteers: a review of commonly encountered stressors, how they cope with them, and implications for volunteer training/management. Am J Hosp Palliat Care 2016;33:201-4.
- 9. Roh SJ, Lim SH. Factors affecting subjective quality of life of hospice volunteers. Korean J Hosp Palliat Care 2011;14:163-71.
- 10. Shim SH. A case study on the experience of hospice volunteers. Korean J Hosp Palliat Care 2016;19:45-60.
- 11. Hu SH, Jung TY. Effects of volunteer activities on self-development and sociability-development of undergraduates: focus on meaning of volunteering. Korean Psychol J Cul Soc Issues 2013;19:133-58.
- 12. Roessler A, Carter H, Campbell L, MacLeod R. Diversity among hospice volunteers: a challenge for the development of a responsive volunteer program. Am J Hosp Palliat Care 1999;16:656-64.
- 13. Meyer D, Schmidt P, Zernikow B, Wager J. It's all about communication: a mixed-methods approach to collaboration between volunteers and staff in pediatric palliative care. Am J Hosp Palliat Care 2018;35:951-8.
- 14. Niinomi K, Soejima M, Hiraga K, Kodama S, Okazaki S, Nakao S. Effectiveness of a volunteer training program on the learning support of children in hospice palliative care. Am J Hosp Palliat Care 2020;37:100-7.
- 15. Kim GR, Hwang HW. The Relationship between volunteer experience and career decision level of university students majoring in social welfare: the mediating effects of self-efficacy and community consciousness. J Korea Contents 2020;20:615-27.
- 16. Yoon MO. Effect of a death preparing education program on death anxiety and meaning of life in volunteers. Korean J Hosp Palliat Care 2009;12:199-208.
- 17. Colazzi PF. Psychological research as the phenomenologist views it. In: Valle RS, King M, eds. Existential-phenomenological alternatives for psychology. New York: Oxford U Press; 1978. p. 48-71.
- 18. Moon YJ, Um MY. A qualitative case study on the pediatric palliative psychosocial support program experienced by parents of children suffering from life-threatening disease. Health Soc Welfare Rev 2020;40:351-91.
- 19. Kubler-Ross E, Kessler D. On grief and grieving: finding the meaning of grief through the five stages of loss. New York: Simon and Schuster Audio; 2005.
- 20. Muckaden MA, Pandya SS. Motivation of volunteers to work in palliative care setting: a qualitative study. Indian J Palliat Care 2016;22:348-
- 21. Padgett D. Qualitative methods in social work research: challenges and rewards. Thousand Oaks, CA: Sage Publications; c1998.