

# A Photovoice Study on the Position and Role of Hospice Volunteers in Korea

Sowon Lee, Boyoung Kim

College of Nursing, Chonnam National University, Gwangju, South Korea

Correspondence: Boyoung Kim, College of Nursing, Chonnam National University, 160 Baekseo-ro, Dong-gu, Gwangju, 61469, South Korea, Tel +82-62-530-4936, Fax +82-62-220-4544, Email bkimjhu@gmail.com

**Purpose:** As the quality of life increases, so does the demand for a dignified life. Although there is an increasing interest in hospice care, which helps people experience a comfortable death, the level of change in perception and in its role remain insignificant.

**Methods:** This study investigated the position and role of hospice care using photovoice, a technique used in Participatory Action Research, to analyze the data collected from hospice volunteers who participated in a training program in Korea.

**Results:** The participants viewed hospice volunteering from the two perspectives: facing unexpected farewells and supporting like bicycle training wheels, highlighting the role of the “connection between death, life, and rest” as a mediator in conflicts between the patients and medical staff. Although the participants dreaded hospice volunteering, it prepared them to share their lives and provided an opportunity for inner growth by expanding knowledge through learning and establishing a “meaningful connection with the community” because they volunteered out of love, not obligation.

**Conclusion:** Because the demand for hospice and palliative care is increasing, this study is meaningful as it investigates the perception of hospice care and determines its influencing factors based on the perspective of hospice volunteers and the changes in their perception over time.

**Keywords:** hospice, volunteer, position, role, photovoice

## Introduction

Advancements in medical technologies have triggered an increase in the global average life expectancy.<sup>1</sup> Due to a longer life expectancy, people are now more interested in the quality of life and in dying with dignity, seeking to learn “how to live” and ensuring a work-life balance, rather than asking “how long can people live?”.<sup>2</sup> The general perception of life changes along with that of patients facing death, such as patients with terminal cancer. A “patient with terminal cancer” refers to a patient with cancer who has no possibility of essential recovery, whose symptoms worsen gradually, and who is expected to die within a few months, regardless of aggressive treatment.<sup>2,3</sup> The term “palliative care for a patient with terminal cancer” refers to medical care aimed at improving the quality of life of such patients and their families by providing comprehensive assessment and treatment of physical, psychosocial, and spiritual aspects, including relief from pain and symptoms.<sup>3</sup> Hospice care is specialized health care for terminally ill patients, helping them to live out a fulfilling life and overcome the fear of death so that they can die peacefully.

An advance directive (AD) on life-sustaining treatment is a document clarifying the patient’s intention for life-sustaining treatment and hospice care, directly in preparation for their end stage period of life.<sup>4</sup> These systems are implemented in many countries; in the United States, people can prepare and register ADs that include parts related to life-sustaining treatment and do-not-resuscitate (DNR) orders.<sup>5</sup> In Japan, guidelines for the decision-making process of end-of-life medical care have been in effect since 2007, and legislations on death with dignity have also been discussed recently.<sup>5</sup> In Korea, the percentage of patients making decisions on life-sustaining treatment increased from 1% to 29% within one year of implementing an act on decisions on life-sustaining treatment for patients in Hospice and Palliative Care in 2018,<sup>4</sup> and the rate of registering ADs on life-sustaining treatment also increased to more than 10,000 a month on

average.<sup>6</sup> The role of hospice volunteers is also becoming important, as it becomes increasingly difficult for family members to care for patients with cancer due to the declining birth rate, reduced number of families, and greater number of women engaging in social activities.<sup>7</sup>

Volunteers play an important role in providing appropriate care to the growing number of hospice patients every year. Although the organization and role of hospice volunteers vary across institutions, they typically focus on tasks that are difficult for the medical staff or social workers to perform, such as listening to the patients and becoming their companions.<sup>8</sup> In Korea, volunteers not only provide physical services such as bathing and massaging patients, but also listen to their stories about their families.<sup>9,10</sup> Greater use of volunteers has been found to be associated with higher levels of service satisfaction as rated by bereaved family members.<sup>11</sup>

Regarding hospice volunteering-related research, a wide variety of studies have been conducted on various themes including emotional well-being and resilience,<sup>12</sup> hospice services during the COVID-19 pandemic,<sup>13</sup> and pediatric hospice care.<sup>14</sup> In Korea, many studies have been conducted on hospice volunteers' perception of death,<sup>15,16</sup> their attitude toward death with dignity,<sup>17</sup> and the meaning of life or the quality of life of volunteers.<sup>18</sup> Although there have also been studies on the experience of hospice volunteers, most are quantitative studies on satisfaction; thus, there is a lack of qualitative studies that take into consideration in-depth reflections or analyses of the experience of volunteers.

Therefore, it is important for those who have received volunteer training to share their experiences in hospice volunteering in order to determine how such experiences affect their lives. Because hospice volunteers in Korea are generally older individuals, they may find it difficult to provide long interviews and express their thoughts in complicated ways. Photovoice is an effective research method in this case, as it allows them to express their thoughts intuitively.

Using photovoice, participants are asked to express their thoughts on research themes through photographs, allowing them to share their points of view or feelings that are difficult to express with language.<sup>19</sup> Photovoice is mainly used for research on minorities who experience difficulties in expressing their thoughts, such as lesbian, gay, bisexual, and transgender<sup>20</sup> or black adolescents.<sup>21</sup> In Korea, there have been studies on individuals with difficulties in expressing their opinions fluently, including people with intellectual disabilities<sup>22</sup> and multicultural adolescents.<sup>23</sup>

The present study took a novel approach in reflecting the experiences of individuals participating in hospice volunteer work by visualizing their thoughts on hospice volunteering. This approach is expected to help change the perception of hospice care by exploring the meaning of hospice volunteering based on participants' daily experiences. Therefore, this study used the photovoice method to investigate how the participants' lives change through their images of and roles in hospice volunteering.

## Materials and Methods

### Study Design, Setting, and Sample

This study used photovoice, a technique used in Participatory Action Research (PAR), to analyze the perception and role of hospice volunteering.

The participants comprised individuals who voluntarily opted to participate among those who had completed training to become hospice volunteers. The inclusion criteria were as follows: The participants had to:

1. Have completed hospice volunteer training,
2. Have had no bereavement experience within the past year,
3. Be under the age of 65 with no reading and writing disabilities, and
4. Be adults who understood the study purpose and methods and agreed to participate in the study.

Wang and Burris<sup>24</sup> suggested that 7–10 individuals was the ideal number of participants for a photovoice study; thus, the sample size of this study was set to 7 participants (six females and one male).

The hospice volunteer training focused on holistic care or, in other words, improving the participants' understanding of death by helping them not only acquire basic knowledge, skills, and attitudes required to cope with physical, emotional, social, economic, environmental, and spiritual issues, but also practice love and care in the community.

The training consisted of 34 h of theoretical education and 10 h of practical training, conducted twice a week for six weeks. Theoretical education comprised contents designed to help terminal patients, patients with cancer, and their families, such as the role and attitude of hospice volunteers, understanding terminal cancer and managing pain, mental and physical health care, and spiritual/end-of-life care. Practical training included home visit practice for home hospice patients, hospital hospice ward practice, hand massage, and foot acupressure methods.

## Procedure

This study used photovoice to examine the perception and role of hospice volunteers, as experienced by the participants. Photovoice is a process through which one can identify, represent, and enhance their community through a specific photographic technique<sup>24</sup> and a theme to express the participants' meaningful experiences.<sup>25</sup> It was developed in 1994 by Wang and Burris,<sup>26</sup> and it uses cameras to express the participants' opinions of the world from their own perspectives.<sup>27</sup>

Using photovoice, participants are asked to share their thoughts and experiences by taking photographs that reflect their mindset and feelings based on a research theme in their lives according to five "SHOWeD" questions.<sup>28</sup>

1. What do you see in this photograph? (See; "S"),
2. What is really happening? (Happening; "H"),
3. How does the story relate to our lives? (Our lives; "O"),
4. Why does this problem or strength exist? (Why, exist; "We"), and
5. What can we do about it? (Do; "D").

Photovoice is generally conducted across five procedures (Preparation → Investigation → Analysis → Sharing → Practice), which presents an opportunity to change the participants' opinions during the process of sharing thoughts through questions.<sup>27</sup>

The research questions that aimed to determine the participants' opinions about hospice volunteering and how they thought it was affecting their lives were presented in each session using the SHOWeD technique. The participants took pictures to express their thoughts. Each session had four themes:

1. What image comes to mind from the term "hospice volunteer?"
2. What is the role of hospice volunteers?
3. How did the hospice volunteer training affect you?
4. How can I contribute to the community by volunteering for hospice care?

## Data Collection

This study conducted four focus group sessions once a week from June 10 to July 5, 2019, in Jinju city, G province, according to the general procedure of photovoice: orientation, photovoice survey, analysis, and sharing.

The participants were informed of the content, purpose, and process of photovoice during the orientation, in addition to being made aware of various ethics and problems that may arise in the process of taking photographs. The research was conducted after informing the participants that the collected data would only be used for research purposes and would be processed anonymously. The participants were also informed to exclude photos that contained personal information (such as faces and names). Their understanding of the study was enhanced by additional information, which helped them participate in the study.

The participants used their mobile phone cameras to take photographs, and they were asked to write down their thoughts and feelings about these photos on an A4-sized paper. These files were sent to the researcher before the meeting. The researcher printed the submitted photographs to share with the other participants during group discussions. The participants were allowed to talk freely for two hours on each theme about what they photographed and what they wanted to express. The sessions were recorded and transcribed after acquiring prior consent from the participants. We recorded the photovoice group activities and transcribed the recordings to maintain documentation of the field activities. We coded the data based on the recordings and derived the domains through consensus.

## Data Analysis

Qualitative analysis was performed according to the six-step thematic analysis method propounded by Braun and Clarke<sup>29</sup> through a series of coding processes. In the first phase, two coders reviewed the transcriptions and photographs from each session and highlighted words and sentences, such as key statements and metaphorical expressions. They also independently developed a coding book for meaningful words, sentences, and paragraphs through line-by-line analysis. During the second phase, open coding was performed by comparing and reviewing the consistency of the coding vocabulary and the similarities and differences of expression. The two coders extracted 82 codes covering all the content. The third phase involved searching for themes by grouping each code into similar concepts, checking whether they matched the themes, and comparing how each theme was conceptualized and interconnected. Thirty-nine sub-themes were extracted from this process, and the data saturation point was confirmed by going over the interviews with the participants. The themes and sub-themes were reviewed by other team members for similarities and differences. The fourth phase involved reviewing the themes, leading to the creation of 4 categories and 8 subcategories from 39 provisional themes according to their common attributes. The fifth phase involved clarifying and naming the themes, during which the researchers identified the themes that were clearly distinct from others while comparing the derived themes. Two participants checked the themes and categories for any misunderstandings or misinterpretations. The sixth phase involved producing a report by defining the statements on each theme and describing the results of each theme by quoting the statements. NVivo 12.0 and Microsoft Excel were used to analyze the discourses.

## Ethical Consideration

The Bioethics Committee of the G University approved this study (GIRB-A19-Y-0034). The first and corresponding authors received IRB approval while attending Gyeongsang National University. The researchers obtained written consent from the participants after explaining the study purpose and methods, information recording for data analysis, confidentiality, and the management of collected data. They were made aware of the various problems that could arise while taking photographs and were assured that the collected data would be processed anonymously and only be used for research purposes. They decided whether or not to participate and were informed of their right to withdraw from the study at any time. They received gift certificates for their participation.

## Rigor of Analysis

This study adhered to the criteria presented by Guba and Lincoln<sup>30</sup> to ensure rigor in qualitative research. To prevent researcher bias before collecting data, we attempted to maintain neutrality to ensure that our knowledge did not influence the participants. Photovoice conducts interviews using photos that reflect the thoughts and experiences of the participants; consequently, prior information about the participants may generate prejudice or bias against them. Therefore, we did not collect background information about the participants before the interviews. We also discussed many potential biases related to the research topic to prevent such distortions in the data analysis stage. Specifically, we anticipated the following biases: the volunteers will not have as much knowledge about hospices as professionals, the volunteers will volunteer because they want to, hospice clients will need volunteers, and the roles of the volunteers will be less professional. We excluded such biases from the analysis.

While conducting the study, we also played a mediating role in the group discussions by giving the participants equal opportunities to speak and encouraging them to share their thoughts candidly. We maintained neutrality by allowing the participants to express their thoughts freely and by working toward preventing our own prejudices and knowledge from influencing the participants.

Additionally, the transcribed files of the interviews were anonymized to prevent any preconceived notions about gender imbalance among the participants from affecting the analysis or the results. To increase the true value, the content was analyzed by perusing the transcripts of the discussions repeatedly with the participants. If there was a conflict, we re-analyzed the original data and focused on the tone of the participant's voice. In the data analysis process, the triangulation method was used to check the applicability of the data analysis to groups other than researchers. The triangulation method was applied to minimize potential errors and biases in the research process and maintain consistency by consulting a nursing professor with experience in photovoice research (see the Audit Trail in [Appendices 1](#) and [2](#)).

## Results

### Participants' General Characteristics

The participants comprised seven individuals, one male and six females. Their ages ranged from 53 to 65 years, with a mean age of 59.14 (standard deviation = 2.15) years. Table 1 shows the general characteristics of the study participants.

### Photovoice Outcomes

In this study, participants were asked to describe the image, role, and community contribution of hospice volunteering, in addition to how the experience of volunteering affected their lives. The results were categorized by theme. The interviews reflected the participants' personal cases, thoughts, and beliefs about hospice volunteering that can be understood in a cultural context (Table 2).

#### Theme 1: Two Perceptions from the Hospice Care Image

In terms of the image of hospice care, the volunteer training participants believed that hospice volunteering involved "facing unexpected farewells" and "serving as a bicycle's training wheels." They mentioned experiencing "sudden deaths" in relationships with hospice care patients and supporting the medical staff to provide care for them.

#### Facing Unexpected Farewells

The participants considered hospice volunteering as the time for discussing and accepting someone's death and facing unexpected farewells. Even though they were aware that most of the patients had terminal cancer or had refused life-sustaining treatment, they expressed their emotions, knowing that some of their patients with whom they talk to on one day may not be there a couple of days later. They also discussed their changing feelings about death, likening it to not only peace but like waves in a calm sea.

**Table 1** General Characteristics of the Participants

ID	Gender	Age	Educational Background	Marital Status	Religion	End-of-Life Care Experience (y)
A	Female	54	College graduate	Married	Christian	More than 5
B	Female	58	High school graduate	Married	Buddhist	1–2
C	Female	65	High school graduate	Widowed	Buddhist	1–2
D	Female	54	College graduate	Married	Buddhist	More than 5
E	Female	65	High school graduate	Married	Catholic	1–2
F	Male	65	College graduate	Married	Catholic	1–2
G	Female	53	College graduate	Married	No religion	3–4

**Table 2** Photovoice Themes and Subcategories

Themes	Subcategories
Two perceptions from the hospice care image	<ul style="list-style-type: none"> <li>- Facing unexpected farewells</li> <li>- Supporting as a bicycle's auxiliary wheel</li> </ul>
Connection roles between death, life, and rest	<ul style="list-style-type: none"> <li>- Mediator between patients, medical staff, and family</li> <li>- A resting place like a bench</li> </ul>
Preparing to share oneself and experiencing inner growth	<ul style="list-style-type: none"> <li>- Fear of starting volunteer work</li> <li>- Expanding knowledge through learning and becoming a volunteer</li> </ul>
Meaningfully connecting with the community	<ul style="list-style-type: none"> <li>- Ubuntu, becoming part of someone's life and family</li> <li>- Volunteering out of love, not obligation</li> </ul>



There will be waves in the sea before it becomes calm; you have to accept death because someday we will all die; but, it's difficult for everyone to accept it. (Participant G)

I really wanted to fly to the hospital when the hospital staff called to inform me that it was time to let him go. But he had not passed away. So, I held his hand and prayed... then, he passed with a very peaceful look on his face. (Participant A)

### Supporting as a Bicycle's Training Wheels

Like bicycle training wheels, the participants considered hospice volunteering to be a supporting role involving diligent help to makes the main character stand out. In Korea, baby's breath flowers are used as decorations or to supplement brighter, prettier flowers. Likewise, the participants also perceived hospice volunteers as people who help and support the patients and medical staff. They also thought of hospice volunteers to be friendly and capable of handling various tasks, likening them to comfortable sneakers rather than formal shoes (Figure 1).

Even though they're not minor roles, they help the lead actor stand out and shine. In hospice care, such quietness lights up the surroundings without revealing its existence. (Participant B)

Hospice volunteers wear flat sneakers and make no noise. They're all so diligent. (Participant D)

## Theme 2: Connection Roles Between Death, Life, and Rest

Hospice volunteers and medical professionals intimately watch over the patients. For the participants, hospice volunteering goes beyond physical care, such as bathing and preventing bedsores, and includes being with the patients so that they can accept death peacefully and spend the rest of their lives comfortably. They view themselves as companions who share the rest of their patients' journey providing psychological care, such as mediating conflicts with the people around them.

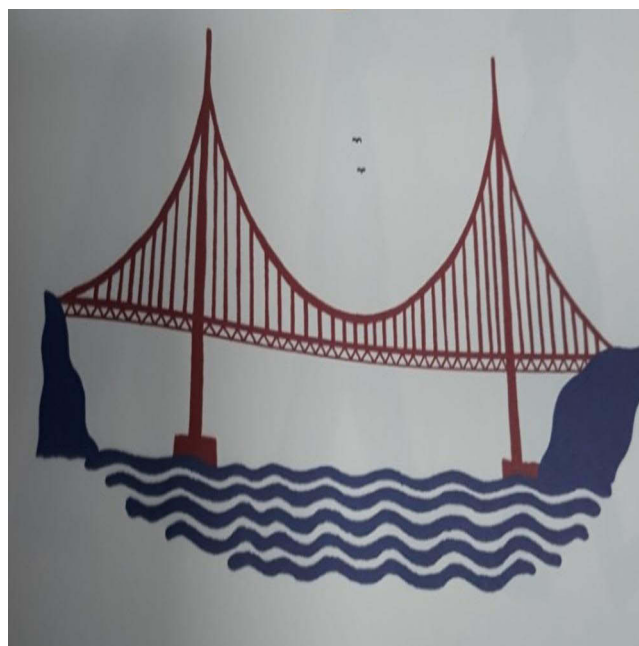
### Mediator Between Patients, Medical Staff, and Family

The participants considered hospice volunteering as a link that connects and ties two different things together, for example, patients and the medical staff and patients and their families. They believed that their role as volunteers involved helping patients when they had conflicts with their families or with the medical staff (Figure 2).

I think of myself as a bridge, or a stepping stone, connecting patients with their families. I want to think that I'm a valued friend of the patients. (Participant C)



**Figure 1** (a) Baby's breath making other flowers stand out; (b) Sneakers that help you walk comfortably.



**Figure 2** A bridge connecting patients with their families and the medical staff.

### A Resting Place Like a Bench

Just like sitting on a bench and taking a break when people get tired of walking, the participants considered the role of hospice volunteering as a resting place where they could stop to listen to the patients and share their suffering (Figure 3).

Screens or shades are used for various purposes. They help people avoid rain and also block out the sun when it is hot outside. People can also rest under a shade when they get tired of walking and when their legs are sore. Volunteers also provide similar services to the patients. (Participant E)



**Figure 3** A shade to block out the sun during hot summers.

### Theme 3: Preparing to Share and Inner Growth

The participants mentioned that the difference between general and hospice volunteering is the people: those who require hospice care are those who are facing the end of their lives. Therefore, hospice volunteers may feel nervous or fearful when they first meet terminally ill patients; however, this fear may help them reflect on their own lives and deaths. After participating in the hospice volunteer training, the participants improved their understanding by learning more about hospice care and volunteering. This change in knowledge and attitude can be viewed as a time of preparation to share one's life and experiences and an opportunity for inner growth before starting the hospice volunteer work.

#### Fear of Starting the Volunteer Work

The participants feared experiencing emotional disturbances while volunteering because the patients who needed hospice care were facing the end of their lives. This fear of starting hospice volunteer work was not just anxiety about what they have not experienced, but also fear of emotional agitation toward their future patients.

I had no confidence at the beginning. They said that I may cry when I go to the hospital to meet the patients, and I felt like I would. I had trouble because of depression, and I walked four hours a day to avoid taking medicine for depression. I came so far without taking any medicine. However, I realized that hospice care is important now that I have also become a person who needs a little bit of comfort. I'm not saying it helped a lot, but I was really grateful to just have a friend. I really think that I recovered by just having a friend. (Participant C)

#### Expanding Knowledge Through Learning, and Becoming a Volunteer

The participants responded positively to expanding their knowledge through education. They also said that such education and training will help them perform volunteer work and prepare them not only for their future life but also to handle separation from their families by death.

It was nice to study and think about what I didn't know and the things that I already knew. The most memorable things were about the end of life and specific medical symptoms. I remember examining people's pulse the most. These two things overlap with my dying mother and my current situation. That's why I can prepare my mind for what comes next. (Participant F)

### Theme 4: Meaningfully Connecting with the Community

The participants expected to engage in meaningful activities as community members through hospice volunteering. They discussed becoming a significant part and person in other people's lives by forming relationships with hospice patients and their families and networking with other volunteers while performing volunteer work.

#### Ubuntu, Becoming Part of the Life and Family of Others

Ubuntu is an Nguni Bantu term meaning "I am, because you are". It describes the relationship or commitment between people. Ubuntu emphasizes that one needs to be with, and not be separated from, others, to grow and profit. Hospice volunteers described the need to share and understand the various emotions they experience in their lives by becoming a part of their patients' lives.

My friend had a good relationship with her husband, but after he died, she had trouble sleeping because she was upset and depressed. She would call me in the middle of the night. I would go over and talk with her and even sleep over sometimes. I think I should take care of a patient in my heart, just like I would take care of a child. (Participant C)

#### Volunteering Out of Love, Not Obligation

The participants described volunteering not as an obligation, but as a heartfelt commitment; and stated that people need to participate in hospice volunteering with the willingness to share their lives. They also said that people need to volunteer out of love for others rather than by viewing hospice volunteering as a job (Figure 4).





**Figure 4** A burning candle to provide light.

I learned things I didn't know, and you need to be sincere if you want to volunteer. People can volunteer out of hurt and pain, but I think you can't really volunteer unless you really love it. I love what people can see on the outside, but you need a heart that loves the invisible soul. (Participant G)

## Discussion

This study used photovoice to investigate the meaning and role of hospice volunteering as perceived by hospice care volunteers.

First, the participants understood hospice volunteering from the two perspectives of facing unexpected farewells and performing the role of a bicycle's training wheels. Although hospice volunteers receive training in hospice care and work over a certain period of time before they start volunteering, their understanding of hospice-related matters was based on their experiences, prior information, or their own limited preconceptions. The participants also perceived hospice care as emotional reactions, labeling it as the "last choice in life" or the "end-of-life" rather than recognizing it as a "treatment". These thoughts were similar to the findings of a study by Kim et al,<sup>31</sup> who investigated differences in perceptions of hospice and palliative care between medical professionals and the general public (patients and guardians). They found that medical professionals perceived hospice and palliative care as holistic care to treat the mind, body, and spirit, while patients and guardians considered it a "service that allows patients with terminal cancer to experience a comfortable death". However, the participants also perceived hospice volunteering as an image of care. Those who experienced the deaths of their parents or spouses tended to discuss hospice care and volunteering by reflecting on their own experiences with their family members. Participants who shared their experiences perceived hospice volunteering as helpful to not only medical professionals in caring for the patients, but also to the patients' families from a broader perspective.

In terms of public perception, there have been studies on hospice care and death in other countries;<sup>32,33</sup> the majority focus on connecting hospice care with emotional well-being.<sup>12,34</sup> However, most of the studies on hospice care in Korea use death or the attitude toward death as a variable; such research has also been performed on various groups, including medical professionals,<sup>35,36</sup> and patients with cancer and their families.<sup>37</sup> On the other hand, studies in the United States focused on life or experience in hospice care rather than on death, including studies related to spirituality<sup>38</sup> and hospice experience.<sup>39</sup> Although hospice care is fundamentally a type of health care to improve the quality of life of terminal patients, in Korea, it is naturally associated with "death with dignity" due to the use of several terms related to death,

such as ADs on life-sustaining treatment and terminal cancer patients. This difference in perception has led to a difference in research themes and has also influenced the perception of the participants toward hospice volunteering.

Second, the participants perceived hospice volunteers as an essential link between death, life, and rest because they played the role of a mediator in conflicts between patients, medical staff, and families. They dreaded starting hospice volunteer work; however, through the training process, they were able to shift their attention to the opportunity for inner growth and to prepare for death by critically reflecting on the role of hospice volunteers in Korea. Before undergoing hospice training, the participants had vague thoughts and were petrified of hospice care; however, after sharing their experiences and completing the training, they recognized the need and importance of hospice volunteers. Their participation in volunteer work became a stepping stone toward inner and self-growth and was not merely an activity. The participants' experiences were similar to the findings of a study by Lee and Yoon,<sup>40</sup> which showed that middle-aged and elderly volunteers began as visitors, then became peers, and ended up becoming one of the patients with terminal cancer with new values, enjoying a sense of unity. In terms of the influence of volunteering, the participants talked about becoming a part of other people's lives as a significant person and of learning new things, expanding their knowledge and experience. Although hospice volunteers fundamentally provide patients with a sense of self-worth, companionship, and respite care,<sup>41</sup> the participants recognized the ability of hospice volunteers to grow and develop themselves rather than just performing simple volunteer activities.

Third, the participants perceived hospice volunteering as a service that involves being with others and building a meaningful connection with the community. Their understanding of hospice care changed to becoming a part of the community. Hospice volunteering can be determined by a person's experience, but it can also be based on the environment and values experienced by the participants. Most of the participants first encountered volunteer work after retirement or in losing family members after taking care of them. They thought that the help of two or three people was more important than the help of just one, likening this to lighting more candles to produce brighter light. The participants used to live for themselves or their families but experienced the joy of contributing as community members while volunteering, escaping from feeling helpless after losing family members or their roles in society. Just as we use candles for various purposes, hospice volunteers perform various roles. They provide services in close contact with patients, but sometimes take a step back at the request of doctors and family members. Hospice care includes activities that are not typically physically demanding, such as being a companion to the patients. However, some activities are physically demanding, such as bathing the patients. Even though hospice volunteers serve various roles, most volunteers in Korea are old, which limits them from performing several activities. This is because the image of hospice care in Korea is related to death and the perception that patients who require hospice care are mostly the elderly. Although there are hospice services for children in other countries,<sup>14</sup> in Korea, the first pediatric hospice was established in 2017, reflecting the limitations of hospice services. During the process of providing palliative care, this study allowed the participants to reflect on their own lives among the traces of others' lives; for example, participants gained indirect experience about death through the deaths of others, gratitude for life, and a sense of how they wanted to be remembered by the people they may leave behind. Considering these points, we believe that photovoice can be used for various groups and topics.

Participants in this study shared various thoughts about volunteering in different roles in hospice care through photography. Most importantly, the participants in this study could demonstrate their subjectivity and initiative to the fullest because they had the desire and will to volunteer. Also, their needs and limitations usually surface, but sometimes they are hidden or lie beyond our awareness. Therefore, the Photovoice methodology was used because it can uncover hidden issues through photos and discourse. This study expanded the use of Photovoice research methods by allowing participants to express themselves with photos depicting matters related to death that may be sensitive and difficult to describe with words. Notably, the study's photovoice methodology has the advantage of expressing yet unacknowledged thoughts. However, since the participants need to understand the overall photovoice research process as accurately as the researcher, differences in the level of understanding and participation may have occurred during participant training. Additionally, because we are accustomed to capturing participants' meanings and contexts, our questions may also have encouraged the participants to simplify their viewpoints.

Owing to the COVID-19 pandemic, this study could not share the thoughts and viewpoints of participants expressed through photos through face-to-face exhibitions in the community. Therefore, alternatively, some photos were used in an online open lecture to train hospice volunteers through Zoom; specifically, they were used to share knowledge about the volunteers' perceptions and roles. As such, there were limitations in the process of transferring the knowledge formed through the presentation to the community. There was also insufficient discussion on how the community understands, evaluates, and uses the acquired or formulated knowledge. The participants were also used to expressing their thoughts with words but not accustomed to expressing them visually through a medium. Despite being instructed on photovoice before the study began, they had difficulties in fully reflecting their thoughts through photographs. Moreover, because this study was conducted not long after the participants began volunteer work, their experiences may not have been fully reflected in their answers. Therefore, it is necessary to obtain more detailed answers reflecting practice in the field through further studies on participants with more experience in hospice volunteer work.

## Conclusion

This study used photovoice to investigate the meaning and role of hospice volunteering, as perceived by participants who completed hospice volunteer training. Specifically, photovoice can be used to understand and uncover a participant's context and their unacknowledged desires, needs, or limitations that may be present but hidden or beyond our awareness through photos and discourse. It examined their thoughts on their influences and how they can contribute to the community. The participants considered hospice volunteers as companions who are prepared for unexpected farewells with the patients and act as mediators between patients, medical staff, and family. They viewed volunteering as an opportunity to grow by sharing their lives as a member of the community. The participants were able to visualize and confirm what they thought about hospice volunteering through photovoice. As time spent on volunteering for hospice care increases in the long term, the process of exploring the participants' perceptions of hospice volunteering, the influencing factors, and the ways of contributing to the community will be meaningful.

## Data Sharing Statement

Data is available upon substantiated request from the corresponding author.

## Ethics Approval and Informed Consent

This study complies with the Declaration of Helsinki and was performed according to ethics committee approval. The Bioethics Committee of Gyeongsang National University approved this study (GIRB-A19-Y-0034). Informed consent was obtained from all participants, including consent to publish their anonymized responses.

## Acknowledgments

The authors would like to thank all the anonymous participants in the hospice volunteer training project.

## Funding

This research was funded by Jinju Health Center in South Korea.

## Disclosure

The authors report no conflicts of interest in this work.

---

## References

1. Seoul Institute [page on the internet]. Seoul: Seoul Institute; 2020. Available from: <https://www.si.re.kr/node/64334/>. Accessed January 8, 2021.
2. Korea National Institute for Bioethics Policy [document on the internet]. Seoul: Korea National Institute for Bioethics Policy; 2016. Available from: [http://nibp.kr/news/2016\\_03/2016\\_03\\_02.pdf](http://nibp.kr/news/2016_03/2016_03_02.pdf). Accessed January 8, 2021.
3. Cancer Control Act [page on the internet]. Sejong-si: Korea Ministry of Government Legislation; 2023. Available from: <https://www.moleg.go.kr/english/>. Accessed October 20, 2020.
4. National Agency for Management of Life-Sustaining Treatment [page on the Internet]. Sejong-si: Korea Ministry of Government Legislation; 2023. Available from: <https://www.lst.go.kr/addt/medicalintent.do>. Accessed January 8, 2021.

5. Lee IH. *Advance Directive Preparation and Application: Survey on Current Activities of Non-Governmental Advance Directive Organizations and Policy Recommendations*. Sejong: Ministry Health and Welfare; 2016.
6. Seo JW. Maeil Business News Korea [page on the Internet]. Seoul: Maekyoung Media Group; 2009. Available from: <https://www.mk.co.kr/news/it/view/2019/01/63819/>. Accessed November 12, 2020.
7. Kim JS. Editorial: present status and future hospice, palliative care in Korea. *Korea J Med*. 2004;67:327–330.
8. Gino S [article on the internet]. Seoul: Featuring; 2023. Available from: <http://www.featureing.co.kr/news/articleView.html?idxno=3254>. Accessed October 20, 2020.
9. Choi SS, Hur HK, Park SM. The analysis of activities of volunteers for hospice care. *Korean J Hosp Palliat Care*. 2000;3:136–143.
10. Kim BH, Jung Y, Park KB. The analysis of activities and satisfaction of volunteers for hospice care. *Korean J Hosp Palliat Care*. 2002;5:163–171.
11. Block EM, Casarett DJ, Spence C, Gozalo P, Connor SR, Teno JM. Got volunteers? Association of hospice use of volunteers with bereaved family members' overall rating of the quality of end-of-life care. *J Pain Symptom Manage*. 2010;39:502–506.
12. Nikihil S, Jo P, Gemma J. 153 A survey to explore the emotional well-being and resilience of a hospice volunteer group. *BMJ Support Palliat Care*. 2020;10:109–163.
13. Walshe C, Pawłowski L, Shedel S, et al. Understanding the role and deployment of volunteers within hospice and specialist palliative care services as they have adjusted to the COVID-19 pandemic. A multi-national EAPC survey. *Palliat Med*. 2022;37:203–214. doi:10.1177/02692163221135349
14. Kirsteen E, Lisa CL. A virtual children's hospice in response to COVID-19: the Scottish experience. *J Pain Symptom Manage*. 2020;60:40–43. doi:10.1016/j.jpainsymman.2020.05.011
15. Kang KS. A comparative study on death orientation and the cognition & nursing needs of hospice in hospice volunteers - a comparison between the trained and nontrained volunteer. *Korean Acad Fund Nurs*. 2003;8:223–233.
16. Choi WS, Choi SN, Suh WK. A study on hospice volunteers' self-efficacy and death anxiety. *Korean J Fam Welf*. 2007;12:193–212.
17. Hwang BD. Attitudes of hospice volunteers towards death with dignity. *Korea Soc Health Serv Manage*. 2011;5:1–14.
18. Roh SH, Lim SH. Factors affecting subjective quality of life of hospice volunteers. *Korean J Hosp Palliative Care*. 2011;14:163–171. doi:10.14475/kjhpc.2011.14.3.163
19. Lee HJ. University students' perceptions on social enterprise using photovoice methodology. *Crisisonomy*. 2015;11:243–268.
20. Kessi S. Photovoice as a narrative tool for decolonization: black women and LGBT student experiences At UCT. *S Afr J High Educ*. 2018;32:101–117.
21. Robin AEA. Asthma disparity photovoice the discourses of black adolescent and public health policymakers. *Health Promot Pract*. 2017;19:213–221. doi:10.1177/1524839917691039
22. Jun JS, Kim KM, Yu DC, Kim DK, Shin YR. Social inclusion of people with intellectual disabilities using photovoice method. *J Intellect Disabil*. 2013;15:305–330.
23. Hong HMR. Community change perceived by participants in the integrated program for early children development with low-income families using photo-voice method: centered on the case of 'seesaw and swing'. *Korean J Soc Welf*. 2014;66:233–255. doi:10.20970/kasw.2014.66.4.010
24. Wang C, Burris MA. Photovoice: concept, methodology, and use for participatory needs assessment. *Health Educ Behav*. 1997;24:369–387. doi:10.1177/109019819702400309
25. Song HS. Critical literacy education of frier and geography education. *Korean Assoc Geogr Environ Educ*. 2003;11:47–64.
26. Lee SJ, Choi SS. Study of alcoholics' life by utilizing photovoice. *Soc Sci Res Rev*. 2014;30:43–71.
27. Lee SW, Kim KS, Kim BY. Exploration of the meaning and factors affecting the mental health perceived by university students utilizing photovoice methodology. *Korean Soc Health Educ Promot*. 2017;34:77–90. doi:10.14367/kjhep.2017.34.1.77
28. Wang CC. Photovoice: a participatory action research strategy applied to women's health. *J Women's Health*. 1999;8:185–192. doi:10.1089/jwh.1999.8.185
29. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3:77–101. doi:10.1191/1478088706qp063oa
30. Guba EG, Lincoln YS. *Fourth Generation Evaluation*. Newbury Park, CA: SAGE Publications; 1989.
31. Kim BH, Kim JH. An inquiry on PR strategy for improving hospice and palliative care awareness. *Commun Theory*. 2018;14:5–49.
32. Ling M, Wang X, Ma Y, Long Y. A review of the current state of hospice care in China. *Curr Oncol Rep*. 2020;22(10):99. doi:10.1007/s11912-020-00959-y
33. Hughes MT, Smith TJ. The growth of palliative care in the United States. *Annu Rev Public Health*. 2014;35:459–475. doi:10.1146/annurev-publhealth-032013-182406
34. Coleman H, Sanderson-Thomas A, Walshe C. The impact on emotional well-being of being a palliative care volunteer: an interpretative phenomenological analysis. *Palliat Med*. 2022;36(4):671–679. doi:10.1177/02692163211064770
35. Lee YE, Choi EJ, Park JS, Shin SH. Perception and knowledge of hospice care and attitude toward death held by medical professionals from the same region in Korea. *Korean J Hosp Palliat Care*. 2013;16:242–252. doi:10.14475/kjhpc.2013.16.4.242
36. Wu H-L, Volker DL. Living with death and dying: the experience of Taiwanese hospice nurses. *Oncol Nurs Forum*. 2009;36(5):578–584. doi:10.1188/09.ONF.578-584
37. Son YJ, Park YR. Perception on hospice, attitudes toward death and needs of hospice care between the patients with cancer and family. *Korean J Rehabil Nurs*. 2015;18:11–19. doi:10.7587/kjrehn.2015.11
38. Stephenson PL, Draucker CB, Martsolf DS. The experience of spirituality in the lives of hospice patients. *J Hosp Palliat Nurs*. 2003;5:51–58. doi:10.1097/00129191-200301000-00020
39. Terri LM, Emilie SP, James P, Randa DS. Experience with hospice: reflections from third-year medical students. *J Palliat Med*. 2002;5(5):721–727. doi:10.1089/109662102320880543
40. Lee BH, Yoon HS. The phenomenological study on the experience of long-term voluntary activities. *Korean Soc Gerontol Soc Welf*. 2015;67:197–226.
41. Marcus DA. The role of volunteer services at cancer centers. *Curr Pain Headache Rep*. 2013;17:376. doi:10.1007/s11916-013-0376-1

**Risk Management and Healthcare Policy**

Dovepress

**Publish your work in this journal**

Risk Management and Healthcare Policy is an international, peer-reviewed, open access journal focusing on all aspects of public health, policy, and preventative measures to promote good health and improve morbidity and mortality in the population. The journal welcomes submitted papers covering original research, basic science, clinical & epidemiological studies, reviews and evaluations, guidelines, expert opinion and commentary, case reports and extended reports. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/risk-management-and-healthcare-policy-journal>