

# The Most Important Aspects for a Good Death: Perspectives from Parents of Children with Cancer

INQUIRY: The Journal of Health Care Organization, Provision, and Financing  
Volume 58: 1–12  
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DOI: 10.1177/00469580211028580  
journals.sagepub.com/home/inq



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## Abstract

A good death is an important concept in pediatric palliative care. To improve the quality of pediatric palliative care, it is imperative to identify which domain is most important for a good death among children with cancer and their parents. This study aimed to (1) assess the essential domains for a good death from the perspectives of parents whose children have cancer using the Good Death Inventory (GDI) and (2) examine which characteristics are associated with the perception of a good death. An anonymous cross-sectional questionnaire was administered to 109 parents of children with cancer. Data were collected using a validated Korean version of the GDI. Descriptive statistics, *t*-test, and ANOVA were used to identify the preferred GDI domains. Multiple linear regression analysis was performed to identify factors associated with the GDI scores. The most essential domains for a good death included “maintaining hope and pleasure” and “being respected as an individual.” The factors most strongly associated with the perception of a good death were end-of-life plan discussion with parents or others and parental agreement with establishing a living will. Encouraging families to discuss end-of-life care and establish a living will in advance can improve the quality of death among children with cancer.

## Keywords

cancer patients, childhood neoplasms, death, hospice and palliative nursing, pediatric oncology nursing

### What do we already know about this topic?

The concept of a “good death” has acquired great importance in pediatric palliative care over the past few decades.

### How does your research contribute to the field?

Communication about end-of-life care can improve the quality of the children’s death, despite not fully understanding it.

### What are your research’s implications towards theory, practice, or policy?

Health care providers may need to provide education on pediatric palliative care, including end-of-life care and a living will for children with cancer, which would help families make decisions and appropriately access hospice and palliative care services.

## Introduction

To bridge the gap between a dying person’s preferences and others’ evaluation of how the person died, it is necessary to determine the patient’s preferences to better assess the quality of dying and death.<sup>1</sup> The concept of a “good death” has acquired great importance in pediatric palliative care (PPC) over the past few decades. Similar to adult patients, PPC for children with life-threatening conditions and their families also requires early integration of services to enhance the provision of holistic care, including its physical, psychological, social, and spiritual aspects.<sup>2,3</sup> Because childhood cancer (ie,

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Received 25 April 2021; revised 1 June 2021; revised manuscript accepted 7 June 2021

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patients aged 0-24 years) accounts for approximately 5% of pediatric deaths in the United States, children with cancer require end-of-life care.<sup>4</sup> In Korea, malignancy (29%) is the leading cause of pediatric death<sup>5</sup> from complex chronic conditions.<sup>6</sup> Moreover, these patients require PPC early after diagnosis, advocating for supportive care throughout the treatment process, and implementing hospice care during the terminal phase.<sup>7</sup>

Efforts have been made to evaluate the quality of death and improve PPC. For instance, Himmelstein et al<sup>8</sup> suggested that PPC can be appropriate for a wide range of conditions, including those for whom “curative treatment is possible” to those with “severe and non-progressive disability conditions.” Siden et al<sup>9</sup> reported on the experiences of North America’s first freestanding hospice, Canuck Place Children’s Hospice, providing fundamental information on the PPC needed. Accordingly, most diagnoses established in the hospice belonged to children with cancer (30%), whose length of stay was the shortest among the groups (median of 60 days),<sup>9</sup> emphasizing the importance of the early introduction of PPC for these patients. Furthermore, after exploring the experiences of bereaved parents of children with cancer, Yoshida et al<sup>10</sup> found that “realizing that the child’s disease was getting worse” was the most distressing experience and that “visiting the room and speaking to the sick child every day” was the most important aspect.

Although much has been achieved in palliative care for adults, less has been contributed to PPC.<sup>11</sup> Despite efforts to disseminate information regarding PPC for children with cancer, Brock et al<sup>12</sup> found no increase in hospice enrollment and no change in the location of death from 2002 to 2014. According to their data,<sup>12</sup> no children with cancer died at home or were enrolled in hospice. Moreover, these efforts have been hindered by the children’s developmental stages and ages, which make it difficult to explore their perspectives regarding a good death.<sup>13</sup> Unfortunately, there is a lack of well-defined, reliable, and validated measures evaluating the quality of death among children. Other difficulties and barriers in implementing PPC for children with cancer have been identified,<sup>7</sup> which include prognostic uncertainty, parental acknowledgment and acceptance, health care providers’ awareness, perception of availability, and a general lack of research. Therefore, obtaining a clear understanding of PPC is important to improve awareness of the benefits of end-of-life care for children with cancer.

### *Measurement for Perception of a Good Death*

Perceptions of good death of an ill child are difficult to measure. Several conditions are considered to select reliable and valid measurement tools. First, the concept of death accepted by children should be considered. A study conducted by Nagy<sup>14</sup> classified the concept of death accepted by children into 3 stages based on age. Children ages 3 to 5 comprehend death as a continuous process of life and regard death as a

temporary separation or a state of sleeping.<sup>14</sup> Children between the ages of 5 and 9 finally understand the existence of death but are still unable to apply the concept to themselves.<sup>14</sup> Lastly, children around the age of 9 realize that death is inevitable and is the termination of physical life.<sup>14</sup> This notion should be considered relevant when determining the wishes of children who are in the final stage of life. Second, cross-cultural validation should be taken into account, such as a Korean version or application to the Korean population.

The Quality of Death and Dying (QODD) was developed to assess the quality of death and is used by family caregivers or health care professionals. It has been translated into other languages, such as Spanish<sup>15</sup> and German.<sup>16</sup> Unfortunately, the QODD has yet to receive a Korean translation and be applied in Korea. Accordingly, the PICU-QODD,<sup>17</sup> based on the QODD for adult patients, takes a more comprehensive and holistic approach, focusing on the hopes and expectations of the family rather than merely on the patients. The Care Evaluation Scale (CES) was developed to assess the quality of care at the end-of-life and was developed in Japan to evaluate the structure, process, and quality of end-of-life care by family members.<sup>18,19</sup> The CES has been translated into English<sup>19</sup> and Korean,<sup>20</sup> with the Korean version found to be methodologically reliable and valid.<sup>20</sup> Lastly, the Good Death Inventory (GDI), developed in Japan, assesses both quality of care at the end-of-life and quality of death and dying. The GDI has been translated into Korean and is reported to be a reliable and valid tool for measuring the perspective of bereaved family members.<sup>21</sup>

## **Background**

All patients have a legal right to prepare an advance directive (AD), which allows them, once incapable, to inform their dying preferences to certain individuals.<sup>22</sup> However, an AD is permitted only for those older than 18 years; otherwise, the parents or legal proxy are authorized to complete and sign the form.<sup>23</sup> The National Hospice and Palliative Care Organization in the United States has provided instructions for ADs to each state since 1967.<sup>24</sup> In the Republic of Korea, according to the National Agency for Management of Life-Sustaining Treatment, the law Life-Sustaining Treatment Decision System was recently established and went into effect in February 2018. In fact, one study revealed that few parents who have children with chronic diseases know about ADs.<sup>25</sup> Although <1-quarter of participants responded that they were familiar with ADs, half of the respondents were willing to making their child an AD.<sup>25</sup> Meanwhile, advance care planning (ACP), which is similar to AD but applicable to all stages of life, is available.<sup>26</sup>

The United Kingdom has been providing ACP for decades.<sup>27</sup> In particular, the National Health Service in the south central of the United Kingdom furnishes a “Child and Young Person’s Advance Care Plan” document and a

guideline that integrates the hopes of a child and their family when it comes to end-of-life circumstances.<sup>26</sup> Since the Republic of Korea having enacted into law the Life-Sustaining Treatment Decision System in February 2018, 493 registered institutions and 295 medical institutions have been designated as National Institutes of Medical Care for Life Prolongation Management.<sup>28</sup> However, despite the legislation for adults in this country, guidelines for children and families still need to be promoted.

Because children with cancer account for most cases of pediatric deaths, they are considered the first to receive palliative care.<sup>5</sup> However, there are few PPC studies involving children with cancer and their parents. Consequently, little information exists on what should be considered first among the various facets of good death when initiating PPC and which factors affect the perceptions of a good death among the parents of children with cancer. Thus, this study (1) assesses the essential domains for a good death from the perspectives of parents whose children had cancer and (2) examines which characteristics are associated with the perception of a good death.

## Methods

### Design, Setting, and Sample

We administered an anonymous cross-sectional survey to parents of children with cancer recruited from the outpatient clinic of the Department of Pediatric Hematology and Oncology at a university hospital in South Korea. Parents whose children (1) were aged between 7 and 18 years and (2) had undergone any stage of cancer treatment (eg, intravenous or oral chemotherapy, transfusion, neutropenic fever treatment, and irradiation) were included. However, we excluded parents whose children (1) were not physically and mentally capable of filling out the questionnaire and (2) had not started any cancer treatment.

### Procedures

Before initiation, the study was approved by the institutional review boards of the 2 authors (2018-0041 and 2018-03-003). Flyers for the study were posted on the hospital bulletin boards and distributed to the outpatient department. A research assistant who received advance training explained the study to the parents, including its purpose, confidentiality, consent, and questionnaire items, and determined the parents' availability. To minimize threats to validity,<sup>29</sup> direct contact between the participants and researchers was avoided, with the RA serving as the direct contact with the participants. Parents who expressed interest and agreed to participate were provided written information and an informed consent form to sign before study participation. Thereafter, parents completed a questionnaire during the visit, with assistance from the RA as needed. A \$10 gift card was provided as compensation.

## Measures

After reviewing all measurement tools assessing quality of death and dying (mentioned in the Introduction section), we determined that the Korean version of the GDI was the most applicable for the Korean population, considering the cultural similarity among Asian countries regarding death. For instance, Korean, Japanese, and Chinese individuals all view illness and death as a natural part of life. Moreover, Korean, Japanese, and Taiwanese individuals are afraid to disclose their true diagnosis and reluctant to discuss death and end-of-life care plans (eg, referral to HPC).<sup>30</sup> The GDI has also been translated into Chinese.<sup>31</sup> Thus, the GDI could be a usable and reliable measurement tool for evaluating perspectives on a good death among Korean individuals.

**The GDI.** The GDI evaluates the perceptions regarding end-of-life care from the perspective of bereaved family members. This tool consists of 18 domains, with each domain having 3 items. Each item is measured on a 7-point Likert-type scale ranging from 1 (*absolutely disagree*) to 7 (*absolutely agree*). We calculated the domain scores based on the mean score for each item. After summing all domains, the total GDI scores ranged from 18 to 126, with higher scores indicating a good death. The GDI assesses physical comfort, relationship status, dignity, and psycho-existential status of end-of-life care.<sup>32</sup>

The GDI is composed of 2 domain categories, core and optional domains. The 10 core domains include physical and psychological comfort, dying in a favorite place, maintaining hope and pleasure, good relationships with medical staff, not being a burden to others, good relationships with family, independence, environmental comfort, being respected as an individual, and life completion. Meanwhile, the 8 optional domains include receiving enough treatment, natural death, preparation for death, control over the future, unawareness of death, pride and beauty, feeling that one's life is worth living, and religious and spiritual comfort.<sup>21,32</sup> The Korean version of the GDI has been translated and validated.<sup>21</sup> The original version of the GDI had a Cronbach's alpha coefficient of 0.94 for internal consistency of the total instrument,<sup>32</sup> whereas the Korean version had a coefficient of 0.93.<sup>21</sup> In the current study, the overall Cronbach's alpha value was .87.

This study aimed to assess the essential domains of a good death among parents of children with cancer. Accordingly, participants were asked to rate the relative importance of each item, after which their responses were measured using a 7-point Likert-type scale ranging from 1 (*absolutely unnecessary*) to 7 (*absolutely necessary*). The feasibility and face validity of the revised GDI were evaluated by 3 parents, and the current study, parents of children with cancer were invited to evaluate the validity of the revised GDI. The final version was proofread and evaluated for grammatical errors by a Korean language and literature expert.

*Characteristics of children with cancer and their parents.* The questionnaire included questions on the demographics of children with cancer and their parents, such as religion, financial status, and education level. Consequently, participants were asked about their children's health status, such as history of pain, perceived health status, and perceived survival rate. Moreover, the questionnaire inquired about the children's end-of-life care and living will, which may be associated with the perceptions of a good death.<sup>33-35</sup>

### Statistical Analyses

All statistical analyses were performed using SPSS, version 25.0 (IBM Corp., Armonk, NY, USA). Descriptive statistics were performed, whereas independent *t*-test, 1-way ANOVA, and post hoc Scheffé's test were conducted to identify mean differences in the GDI domain scores according to the participants' demographic characteristics. We divided the characteristics of continuous variables into 2 groups using the median. Finally, we performed hierarchical multiple linear regression analysis to determine factors associated with the GDI scores using variables found to be significantly associated with GDI scores during univariate analysis. Blocks of variables were entered into the perception of a good death outcome based on a logical sequence. "Perceived health status" was entered first given that this was the only variable to show a significant difference among demographic characteristics. "Patients'" discussion of their end-of-life plan with parents or others was added in the second step to assess their incremental validity after controlling for perceived health status. "Parents'" agreement with the patient having a living will was entered as the last step to assess their incremental validity after controlling for the previous 2 variables. All assumptions in the multiple linear regression analysis conducted via residual analysis were satisfied. Statistical significance was set at  $P \leq .05$ .

## Results

### *Characteristics of the Children with Cancer and their Parents*

Among the 120 parents surveyed, 109 questionnaires were analyzed. A total of 11 parents had incomplete survey data for the following reasons: insufficient time and inability to focus on answering the surveys for caring their children. Table 1 presents the demographic characteristics of the 109 parents and their children with cancer are described. Most parents were female ( $n=93$ , 85.3%), and half were religious ( $n=55$ , 50.9%). The frequency of religious activities per week was 1.28 (standard deviation [SD]=1.56). The mean age of the children with cancer was 9.65 years (SD=5.88 years), more than half of whom were male ( $n=60$ , 55.0%). On average, children were diagnosed with childhood cancer for 3.66 years (SD=3.58 years).

Children with cancer perceived their health status to be neutral ( $n=52$ , 48.1%). Although more than half were actively participating in treatment decision making ( $n=61$ , 56.4%), most children with cancer had not discussed their end-of-life plans with their parents or others ( $n=82$ , 75.9%). Most parents agreed with having their children participate in establishing a living will in advance ( $n=89$ , 82.4%), whereas approximately half wanted the living will to contain only pain control but not prolonged life extension ( $n=47$ , 52.8%).

### *Relative Importance of Each Domain for a Good Death*

Table 2 and Figure 1 summarize GDI total and domain scores. Higher GDI scores indicate more importance for a good death based on the perspectives of the parents of children with cancer. The mean total score for all 18 items was 107.47 (SD=6.02; range, 18-126). "Maintaining hope and pleasure" and "being respected as an individual" were the items with the highest scores, indicating that these were the most important domains for a good death. The item with the lowest score was "pride and beauty," indicating that it was the least important domain for a good death.

### *Differences in GDI Scores According to the Characteristics of the Children with Cancer and their Parents*

Table 3 shows the mean differences in total GDI scores according to the characteristics of the children with cancer and their parents. Good perceived health status was significantly associated with higher GDI total score ( $F=4.87$ ;  $P=.009$ ) as compared with neutral and bad conditions. Children with cancer who had discussed their end-of-life plans with their parents or others obtained significantly higher total GDI scores ( $t=-6.44$ ;  $P=.001$ ) than those who had not. Parents who agreed with their children in establishing a living will had significantly higher GDI total score ( $t=-5.19$ ;  $P=.001$ ) than those who did not.

### *Factors Associated with the Perception of a Good Death*

To identify the critical variables associated with better perception of death, we performed hierarchical linear regression analysis. Accordingly, univariate analysis identified the following 3 significant variables (Table 3) in the hierarchical linear regression analysis: (1) perceived health status, (2) patients' discussion of end-of-life plan with parents or others, and (3) parental agreement with the patient establishing a living will. We found no multicollinearity of the data; for instance, the ranges were 0.73 to 0.90 for tolerance and 1.11 to 1.40 for variation inflation factor. Independence of residuals was 1.610, as verified using the Durbin-Watson statistic.

**Table 1.** Characteristics of Children with Cancer and their Parents (N= 109).<sup>a</sup>

Variables	M	SD	n	%
Parents of children with cancer				
Sex				
Female			93	85.3
Male			16	14.7
Marital status				
Unmarried			2	1.9
Married			101	93.5
Divorced			5	4.6
Number of children				
1			29	26.9
2			65	60.1
More than 3			14	13.0
Religion				
Yes			55	50.9
No			53	49.1
Religion type (yes)				
Christian			20	36.4
Catholic			8	14.5
Buddhist			26	47.3
Other			1	1.8
Frequency of religious activities (per week)	1.28	1.56		
Financial status				
High			1	0.9
High-middle			13	12.0
Middle			68	63.0
Middle-low			19	17.6
Low			7	6.5
Educational level				
Middle school			1	0.9
High school			35	32.4
University and above			72	66.7
Children with cancer				
Age	9.65	5.88		
Years post diagnosis	3.66	3.58		
Sex				
Female			49	45.0
Male			60	55.0
Diagnosis				
Hematology			52	47.7
Leukemia and lymphoma			34	31.3
Solid oncology			23	21.1
Educational level				
Preschool			39	36.1
Elementary school			36	33.3
Middle school			13	12.0
High school			11	10.2
Other (university, home schooling)			9	8.3
Perceived health status				
Very good condition			10	9.3
Good condition			28	25.9
Neutral			52	48.1
Bad condition			15	13.9

(continued)

**Table 1. (continued)**

Variables	M	SD	n	%
Very bad condition			3	2.8
Participation in treatment decision making				
Very active participation			17	15.7
Active participation			44	40.7
Passive participation			15	13.9
Follows parents' decision			32	29.6
Discussion of children with cancer's end-of-life plan with parents or others?				
Yes			26	24.1
No			82	75.9
Parents agree with their children having a living will?				
Yes			89	82.4
No			19	17.6
If yes (n=89), content of the living will?				
Receive all treatments to prolong life			42	47.2
No prolonged life, only pain treatment			47	52.8

M=mean; SD=standard deviation.

<sup>a</sup>Total N does not equal 109 because of missing values.

**Table 2. Relative Importance of Each Domain for a Good Death (N= 109).**

Domains	M	SD
1. Physical and psychological comfort	6.69	0.49
2. Dying in one's favorite place	6.57	0.59
3. Maintaining hope and pleasure	6.73	0.50
4. Good relationship with medical staff	6.60	0.52
5. Not being a burden to others <sup>a</sup>	4.01	1.92
6. Good relationship with one's family	6.67	0.46
7. Independence	6.07	0.93
8. Environmental comfort	6.11	0.88
9. Being respected as an individual	6.73	0.42
10. Life completion	6.55	0.66
11. Receiving enough treatment	6.65	0.49
12. Natural death	6.32	0.69
13. Preparation for death	6.60	0.52
14. Control over the future	5.56	1.19
15. Unawareness of death	5.96	0.84
16. Pride and beauty <sup>a</sup>	2.32	1.00
17. Feeling that one's life is worth living	6.44	0.63
18. Religious and spiritual comfort	4.88	1.63
GDI total score (All 18 domains; range: 18-126)	107.47	6.02

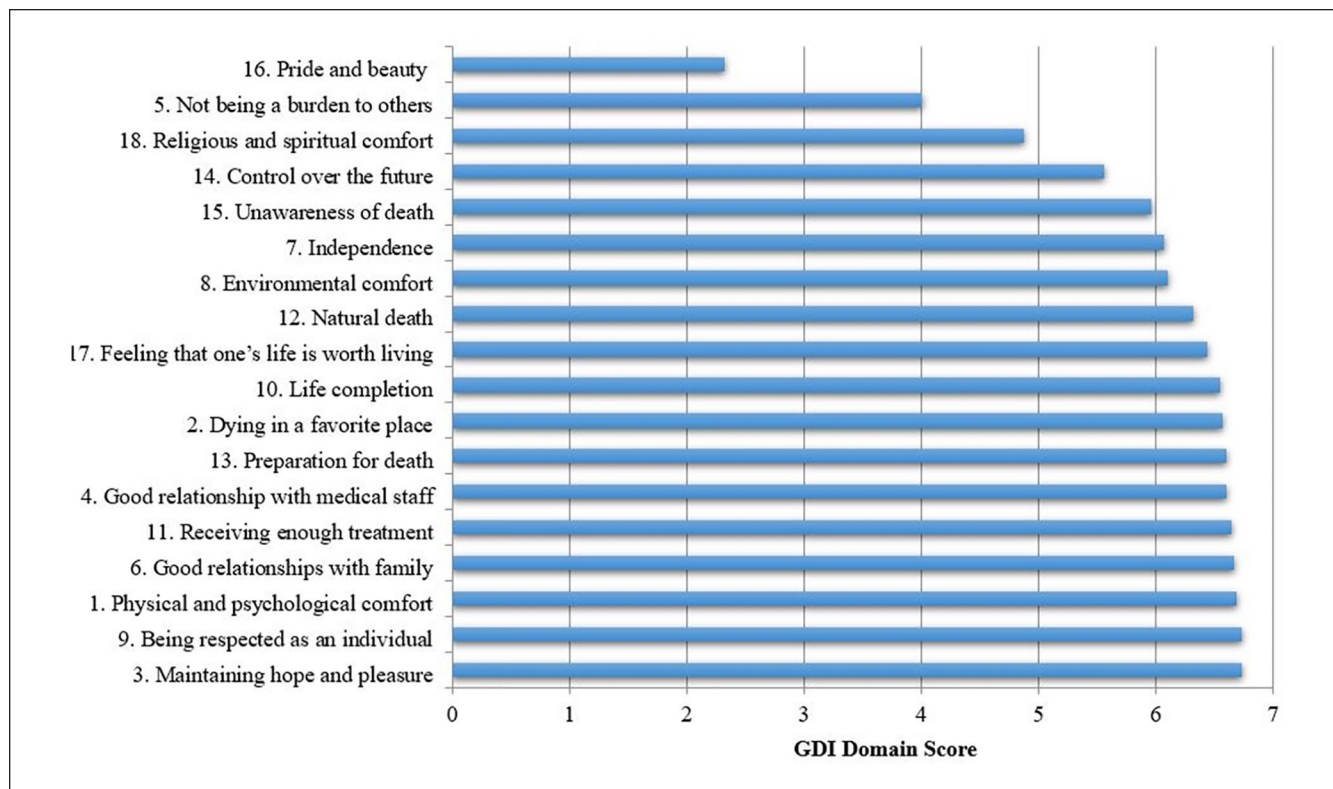
M=mean; SD=standard deviation.

<sup>a</sup>Domain composed of inverse items.

Results of hierarchical multiple linear regression analyses (Table 4) indicated that perceived health status, patients' discussion of their end-of-life plan with parents or others, and parents' agreement with patient establishing a living will explained a significant amount of variance in the perception of a good death (Adjusted  $R^2=0.38$ ;  $F=17.48$ ;  $P<.001$ ). Each block of factors explained a significant amount of variance: perceived good condition of health status explained 7% of the variance when entered first, patients' discussion of

their end-of-life plan added a further 29% on the second step, and parents' agreement with the patient establishing a living will provided an additional 38%.

In the final model, both patients' discussion of their end-of-life plan ( $\beta=.42$ ,  $P=.001$ ) and parents' agreement with the patient establishing a living will ( $\beta=.33$ ,  $P=.001$ ) were strong predictors of the perception of a good death. However, good perceived health status was not identified as a significant predictor ( $\beta=.12$ ,  $P=.179$ ).



**Figure 1.** Relative importance of each domain for a good death. The Good Death Inventory (GDI) consists of 18 domains. Each bar represents the mean GDI domain score. Mean scores are listed in the order of lowest to highest, with higher scores indicating better perception of a good death.

**Table 3.** Differences in Perceptions Regarding a Good Death According to the Characteristics of Children with Cancer and their Parents (N= 109).

Variables	n	GDI total score	
		M (SD)	t or F (P)
Sex			
Female	92	107.83 (5.81)	-1.47 (.144)
Male	16	105.44 (6.99)	
Number of children			
1	28	107.65 (6.43)	0.17 (.841)
2	65	107.27 (6.15)	
More than 3	14	108.29 (4.98)	
Religion			
Yes	55	107.47 (6.35)	-0.05 (.960)
No	52	107.53 (5.77)	
Frequency of religious activity (per week)			
< 1/week	16	104.75 (5.33)	-1.83 (.073)
≥ 1/week	34	108.18 (6.52)	
Financial status			
High	14	108.33 (7.58)	0.52 (.597)
Middle	67	107.04 (5.72)	
Low	26	108.24 (6.11)	

(continued)

**Table 3. (continued)**

Variables	n	GDI total score	
		M (SD)	t or F (P)
<b>Educational level</b>			
High school or less	35	106.28 (6.23)	-1.47 (.145)
University and above	72	108.10 (5.91)	
<b>Age</b>			
≤9	54	107.46 (5.22)	-0.03 (.979)
>9	54	107.49 (6.78)	
<b>Years after diagnosis</b>			
≤2	53	107.06 (6.45)	-0.77 (.443)
>2	54	107.96 (5.62)	
<b>Sex</b>			
Female	49	108.58 (5.86)	-1.76 (.082)
Male	59	106.55 (6.06)	
<b>Diagnosis</b>			
Hematology	51	107.50 (6.11)	1.04 (.358)
Leukemia and lymphoma	34	106.50 (5.67)	
Solid oncology	23	108.84 (6.32)	
<b>Educational level</b>			
Preschool <sup>a</sup>	38	106.20 (5.32)	1.47 (.235)
Elementary school <sup>b</sup>	36	107.92 (5.47)	
Middle school or higher <sup>c</sup>	33	108.55 (7.22)	
<b>Perceived health status</b>			
Good condition <sup>a</sup>	29	110.31 (5.95)	4.87 (.009) a > b,c
Neutral <sup>b</sup>	41	106.78 (4.39)	
Bad condition <sup>c</sup>	38	106.05 (6.95)	
<b>Participation in treatment decision making</b>			
Very active participation	17	107.12 (6.52)	1.25 (.297)
Active participation	43	107.84 (6.05)	
Passive participation	15	109.73 (6.68)	
Follows parents' decision	32	106.21 (5.37)	
<b>Patients' discussion of their end-of-life plan with parents or others</b>			
Yes	28	112.84 (4.33)	-6.44 (.001)
No	80	105.59 (5.37)	
<b>Parents' agreement with patient having a living will</b>			
Yes	84	108.92 (5.31)	-5.19 (.001)
No	23	102.30 (5.79)	
<b>If yes, content of the living will?</b>			
Receive all treatments to prolong life	40	109.16 (5.71)	0.56 (.111)
No prolonged life, only pain treatment	44	107.14 (6.01)	

M = mean; SD = standard deviation.

<sup>a,b,c</sup>Scheffé's test.

## Discussion

This is the first study to assess the essential domains of a good death from the perspectives of parents whose children have cancer and to examine factors associated with perception of a good death using the GDI. Our results demonstrated that the most essential domains for a good death were "maintaining hope and pleasure" and "being respected as an individual." Moreover, factors most associated with the perception of a good death included patients' discussion of

end-of-life plans with their parents or others and parents' agreement with the patient establishing a living will.

### *Relative Importance of Each Domain for a Good Death between Pediatric and Adult Patients with Cancer*

A study on the GDI scores among bereaved family members in Korea reported that "being respected as an individual" and



“good relationship with medical staff” were the most important domains.<sup>21</sup> Furthermore, another study surveying the general Chinese population and health care providers using the GDI reported that a “good relationship with family” and “being respected as an individual” had the highest scores.<sup>31</sup> The results of the aforementioned studies were similar to those presented herein, suggesting that “being respected as an individual” is the most important domain for both pediatric and adult patients. Communicating serious medical issues with children suffering from cancer and their families is anything but easy, with PPC experts emphasizing the importance of having trusting and respectful relationships with the patients over time.<sup>3</sup> The setting, perception, invitation or information, knowledge, empathy, and summarize or strategize (SPIKE)S framework<sup>36</sup> could provide a 6-step method to guide clinicians in communicating with patients and their families. However, health care providers should be reminded that children and their families need to be respected as individuals first, even when the children are approaching death.

### *Discussion of End-of-Life Plan with Parents or Others*

“Death” has remained a taboo subject among Asian cultures, including South Korea,<sup>31</sup> which makes it challenging for parents to communicate with their children regarding their terminal condition and end-of-life plans. Furthermore, children have immature notions regarding the 5 essential components of a mature concept of death.<sup>37</sup> Consequently, both children and their parents become reluctant to have an open conversation about death, which can lead to a situation called “mutual pretense,”<sup>38</sup> whereby both children and their parents are aware of the impending death but neither are willing to discuss it.<sup>34</sup> Indeed, parents who discussed death with their child felt positive about having had the conversation on end-of-life care,<sup>34</sup> which reinforces the importance of an end-of-life care plan. When patients included in the current study communicated about their end-of-life care with their parents, the parents presented better perceptions on death, as illustrated by the higher GDI core domain and total scores. This finding may indicate that communication about end-of-life care can improve the quality of the children’s death, despite not fully understanding it. Furthermore, a study found that most parents who decided to talk with their children about their impending death felt assured in their decision.<sup>34</sup> Moreover, another study showed that earlier and more often discussions on PPC had mutual benefits for both the children and their parents.<sup>35</sup> Therefore, health care providers should attempt to foster open communication regarding death between all concerned parties.

### *Parents’ Agreement with the Patient Establishing a Living Will*

Most parents agreed that the patients should establish a living will, leading to better perception of death. With regard to

the content of the living will, however, half of the parents still wanted their children to receive all treatments to prolong life, not PPC, which could pose a possible barrier for patient enrollment into palliative care during the earlier stages of their illness. Similar to palliative care for adults, PPC should include not only the final weeks of their life but also a prolonged period of chronic complex care.<sup>9</sup> However, parents may still want their children to receive all possible intensive and life-sustaining treatment, thereby resulting in a hesitation to initiate PPC.

Interestingly, parents who wanted their children to receive all treatments had higher GDI scores than those who wanted PPC. Despite the ineffectiveness of treatment for terminal conditions, stopping treatment seems to generate feelings of guilt among parents. However, a study comparing aggressive chemotherapy with supportive care alone reported that the choice of aggressive chemotherapy predicted significantly more severe pain for children with cancer.<sup>39</sup> A more recent review found that children with cancer had several concurrent symptoms during the end-of-life period.<sup>40</sup> Therefore, health care providers should ensure that the best prognostic information is provided to children with cancer and their parents to suggest less painful approaches for improving the quality of end-of-life, such as PPC. Despite parents’ knowledge regarding the discouraging prognosis, they might not feel deprived of hope if their children receive appropriate PPC.

It is important to implement early integration between palliative care services and standard oncologic care for patients with cancer, and its proper timing has been emphasized in previous studies.<sup>41,42</sup> After comparing the perceived timeliness of palliative care enrollment among patients, one study showed that those who were promptly admitted to the palliative care unit had significantly higher GDI scores than those admitted later.<sup>43</sup> In the aforementioned study, pediatric patients and their caregivers were more frequently observed in groups admitted to the palliative care unit much later in the treatment course.<sup>43</sup> Considering that 1-quarter of patients passed away within 1 week after palliative care enrollment in Korea,<sup>44</sup> both advanced care and end-of-life care planning that considers the needs of the patients and their parents are critical and need to be implemented as soon as possible throughout the course of treatment.<sup>8</sup> To provide proper PPC services to pediatric patients and their families, their understanding and willingness to partake in PPC services should be confirmed before treatment through a living will or end-of-life plan. To accomplish this, education about PPC should be provided to pediatric patients and their families before the patients reach the terminal stages.

### *Strengths and Limitations*

This study is the first to assess the essential domains of a good death among parents of children with cancer and to

**Table 4.** Factors Associated with the Perception of a Good Death.

Variables	R <sup>2</sup> =0.08, adjusted R <sup>2</sup> =0.07, F=4.78, P=.010			R <sup>2</sup> =0.31, adjusted R <sup>2</sup> =0.29, F=15.50, P<.001			R <sup>2</sup> =0.41, adjusted R <sup>2</sup> =0.38, F=17.48, P<.001					
	B	SE	β	t (P)	B	SE	β	t (P)	B	SE	β	t (P)
Constant	106.05	0.95	—	111.93 (.001)	104.99	0.85	—	124.18 (.001)	102.00	1.08	—	94.46 (.001)
Perceived health status <sup>a</sup>	0.79	1.32	.06	0.60 (.552)	0.17	1.16	.01	0.15 (.882)	-0.54	1.09	-.04	-0.49 (.625)
Good condition	4.26	1.44	.32	2.97 (.004)	2.54	1.29	.19	1.97 (.051)	1.66	1.22	.12	1.35 (.179)
Discussion of end-of-life plan with parents or others <sup>b</sup>					6.70	1.15	.49	5.82 (.001)	5.71	1.10	.42	5.19 (.001)
Parents' agreement with establishing a living will <sup>b</sup>									4.78	1.18	.33	4.05 (.001)

SE = standard error; β = standardized beta.

Reference groups: <sup>a</sup>Bad condition.<sup>b</sup>No.

examine the relative importance of each domain using the GDI. Moreover, we were able to examine factors associated with a better perception of death using the characteristics of the patients and their parents. However, this study has several limitations. First, the age of the children with cancer ranged from 1 to 20 years. Therefore, the perceptions of a good death among parents may vary according to their child's developmental stages. Second, given that the participants were recruited from the outpatient department, children with cancer had relatively good health compared with those admitted to the hospital for active treatment. Thus, the overall responses may not reflect the exact perception of the quality of death among parents of children with cancer. Therefore, further research on this topic during the bereavement period is highly recommended. Lastly, the generalizability of these findings may be limited given that our sample was composed predominantly of Korean individuals. However, our findings should be applied to the broader Asian population.

## Conclusions

Our findings indicate that parents of children with cancer considered "maintaining hope and pleasure" and "being respected as an individual" as the most essential domains for a good death. Moreover, discussions regarding an end-of-life plan with parents or others and parental agreement with the patient establishing a living will were associated with better perception on death. Thus, our study provides pertinent information regarding a good death from the perspectives of parents whose children had cancer. To improve the quality of death among children with cancer, it is imperative to encourage them and their parents to discuss end-of-life care in advance. In addition, to help guide the children and their parents in deciding whether to access PPC services when appropriate, education regarding the establishment of a living will is important. Future research involving the perspectives of a good death among children with cancer, along with those of their parents, will provide a more comprehensive insight into the effects of PPC.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Research Foundation of Korea (NRF) grant funded by the Government of Korea (MISP No. 2016R1C1B2013649) for study design and data collection, as well as the National Research Foundation of Korea (NRF) grant funded by the Government of Korea (MSIT No. 2020R1C1C1010602) for data analysis, manuscript development, and publication.

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