

Original Article

Qualitative Study on the Perceptions of Terminally Ill Cancer Patients and Their Family Members Regarding End-of-Life Experiences Focusing on Palliative Sedation

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Abstract

Context. Patients with terminal cancer experience refractory symptoms in the last days of life. Although palliative sedation (PS) is recommended for patients suffering unbearable symptoms with imminent death, it requires clear communication between physicians and patients/caregivers. Understanding the demands and perceptions of patients and caregivers in the end-of-life phase are needed for effective communication.

Objective. To explore patient experiences regarding end-of-life status and PS.

Methods. The study was performed between October and December, 2013 with eligible terminal cancer patients and their families in a non-religious, tertiary healthcare facility in Korea. Eligibility criteria were a hospitalized cancer patient with a life expectancy of less than three months and who had never experienced PS. Data were collected via face-to-face in-depth interviews and analyzed using the constant comparative method of qualitative analysis. Saturation was achieved after conducting interviews with 13 patients or care-giving family members.

Results. Enrolled patients raised the following issues: 1) simultaneously harboring the hope of prolonging life and wishing for a peaceful death, 2) experiencing difficulties in having honest conversations with caregivers regarding death, 3) possessing insufficient knowledge and information regarding PS, and 4) hoping for the decision on PS to be made before suffering becomes too great.

Conclusion. Terminally ill cancer patients and their caregivers expressed conflicting desires in hoping to prolong life and simultaneously wishing to experience a peaceful death. Improvements in the communications that occur among physicians, patients, and caregivers on the issues of prognosis and PS are needed. *J Pain Symptom Manage* 2017;53:1010–1016. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Conscious sedation, communication, terminal cancer, caregivers, qualitative research

Introduction

The symptoms of terminally ill cancer patients vary widely and are difficult to treat. In the two weeks leading up to death, 30%–88% of terminally ill cancer patients experience diverse symptoms, including fatigue, vomiting, pain, loss of appetite, dyspnea, and changes in mental status.¹

Palliative sedation (PS) is a last resort for terminally ill cancer patients experiencing continuous and intolerable suffering despite various therapeutic attempts to relieve suffering and whose life expectancy is measured in weeks.² PS is simply intended to reduce a patient's level of consciousness to the extent that suffering is no longer perceived and generally does not hasten

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death.^{3,4} The ethical justification for and treatment adequacy of PS have been verified.^{5,6} Guidelines from the European Association for Palliative Care, National Comprehensive Cancer Network, and National Hospice and Palliative Care Organization were developed regarding the use of PS in patients with certain indications and life expectancies. Refractory physical suffering is considered an appropriate indication for the use of PS, while controversial indication for alleviating psychosocial distress. Agreement on the timing of initiating PS varies from hours to weeks of life expectancy.⁷⁻⁹ It has been reported that 67% of patients who were suffering from refractory symptoms and could express their opinions in their last moments actually asked for PS.¹⁰ In addition, when PS was actually implemented, patients' family members were generally satisfied with the use of this therapy.^{11,12}

The prevalence of PS has wide range (0%–36%) depending on the care setting, culture, and nation.¹³ According to previous studies, only 2% of patients receive PS before death in Korea, whereas 25% receive PS in Italy.^{13,14} This limited application might be attributed to a lack of understanding of caregivers' concerns and knowledge about PS. Patients' caregivers may feel a burden when they consider PS to be similar to euthanasia. Some caregivers may also prefer maintaining consciousness over relieving symptoms by reducing awareness or vice versa.

As for the perspectives of patients, achieving the relief of symptoms, avoiding inappropriate prolongation of the process of dying and strengthening relationships with loved ones are important points for improving end-of-life quality.¹⁵ Therefore, before implementing PS, a consensus for its necessity should be reached among the patient, the patient's physicians, and the patient's caregivers, if possible. Thus, investigation of the demands and perceptions in the end-of-life phase is needed. Several studies have been conducted to evaluate the perceptions of medical professionals regarding PS.^{16,17} However, scarce qualitative studies regarding the perceptions of terminally ill cancer patients and their caregivers with respect to PS have been performed.¹⁸ The purpose of the present study was to gain insight into the perceptions of terminally ill cancer patients and their family members regarding a patient's end-of-life status and their need for PS using qualitative, in-depth interviews.

Methods

Study Design

The present study was performed to gain an understanding of the thoughts and feelings experienced by terminally ill cancer patients and their family members with respect to a patient's end-of-life status, their

need for PS, and their decision-making process through in-depth interviews.

Study Subjects

The following inclusion criteria were used: 1) a hospitalized, terminally ill cancer patient with a life expectancy of less than three months, 2) both the patient and their family members were aware of the patient's terminal status, 3) the patient and/or their family members were able to explicitly express their intentions with clear consciousness, 4) the patient and/or family members were fully capable of participating in an interview, 5) the patient had never experienced sedation for the purpose of relieving refractory suffering, and 6) the patient voluntarily participated in the study.

The following exclusion criteria were used: 1) a lack of understanding regarding the purpose of the study by the patient or their family members, 2) a patient likely to have difficulty participating in a face-to-face meeting due to their existing psychiatric history, seizures, or central nervous system disorders, and 3) a patient whose death was imminent (i.e., within days).

Data Collection and Study Procedures

The study was performed between October 1, 2013 and December 31, 2013 in a non-religious, tertiary healthcare facility in Korea. Interviews for data collection were conducted after written informed consent was provided. The interviews were conducted by a researcher experienced in qualitative studies who had no prior relationship with the interviewees. The interviews were performed in a designated interview room, and they were recorded after receiving written informed consent.

In Asia, family members tend to think that they have a decision-making authority and responsibility for the patient, even when the patient is fully competent.¹⁹ Thus, before calling for the interview, the authors inquired about favorable interview settings due to the sensitivity of these issues. The preferences were divided into three categories: patient only, family only, or both. If desired, the interviews were conducted with both the patient and his/her caregivers present. In two cases, patients were interviewed directly; in three cases, patients were interviewed together with their family members; and in eight cases, interviews were conducted with family members only.

We used a prepared-interview strategy. Serial questions were asked, starting from establishing comfort in the discussion and moving on to the central aspects of the issues related to PS.

The following questions were asked:

1. "What is the current status of the patient? Is there any discomfort such as pain, dyspnea?"

2. "What are the current treatments you are receiving for terminal cancer?"
3. "Can you tell me about how you would feel if the cancer is aggravated?"
4. "Have you ever imagined you or your family member dying?"
5. "How would you like your physician or attending medical staff to ensure that you experience a peaceful death?"
6. "Have you ever demanded something such as symptom relief when you or your family member's condition got worse?"
7. "When the condition of the patient became worse, have you ever told the doctor that you hope that it or have to do it? If you told it, please tell me the contents of the requests; If you did not tell that, please tell me why do not do that."

After the interviews were complete, the contents of the interview recordings were transcribed for subsequent data analysis. Data collection was finished when the data were considered saturated, which occurred when the themes derived from the data analysis appeared repeatedly in subsequent rounds of analysis. Saturation was reached after conducting interviews with 13 patients or care-giving family members.

The mean interview times were 21 minutes for the patients and 45 minutes for the caregivers.

Data Analysis

The collected interview data were analyzed via a content analysis. The content analysis was conducted by repeatedly reading the data to thoroughly understand its contents and then collecting significant or relevant statements. Following this, themes were derived from the collected data. For this purpose, two researchers independently extracted meaningful statements from the recorded transcripts. Statements that were consistently selected were further examined. These statements were then classified into sub-themes and re-named under broader theme umbrellas. The

total number of meaningful statements was 128, which were grouped into three broad themes and eight sub-topics.

Quality Assurance

To ensure the quality of the research, the following four criteria were considered: reliability, auditability, transferability, and confirmability.²⁰ To ensure the reliability of the analysis, two researchers independently analyzed the data and then compared their results. These results were verified by another researcher to further ensure the reliability of the analysis.

Auditability was established by analyzing the data according to the content analysis and presenting the raw data regarding each theme. Transferability in this study involved ensuring the applicability of the collected data for other similar studies. This was partially achieved by collecting data such as sex, age, and disease state from the 13 terminally ill cancer patients and their caregivers. Using the above methods for establishing reliability, transferability, and auditability, neutral results unaffected by the researchers' prejudices or biases could be obtained. Through this process, confirmability was ensured. This study was approved by the Institutional Review Board at our institution (IRB No: GNUH 2013-09-014-005).

Results

General Characteristics of the Study Subjects

Thirteen terminally ill cancer patients, including eight males and five females aged between 32 and 81 years old (mean, 60.5 years), were enrolled. Detailed demographic information about these patients, including primary cancer, level of education, and marital status, is provided in [Table 1](#).

End-of-Life Experience

Holding Out Hope of Prolonging Life. All the enrolled patients had been notified of their terminal status by

Table 1
General Characteristics of the Study Subjects

ID	Patient Sex	Patient Age	Diagnosis	Academic Background (School)	Marital Status	Interviewee(s)
1	Male	65	Cholangiocarcinoma	Elementary	Married	Family (wife)
2	Male	56	Cholangiocarcinoma	Elementary	Divorced	Family (ex-wife) + patient
3	Female	81	Stomach cancer	Elementary	Widowed	Patient
4	Female	54	Cholangiocarcinoma	Junior high	Married	Patient
5	Female	72	Colon cancer	Junior high	Married	Family (husband)
6	Male	67	Colon cancer	Elementary	Married	Family (wife)
7	Male	66	Cholangiocarcinoma	Junior high	Married	Family (wife) + patient
8	Male	73	Colon cancer	Junior high	Married	Family (wife) + patient
9	Male	64	Pancreatic cancer	High	Married	Family (wife)
10	Female	42	Stomach cancer	University	Married	Family (husband)
11	Female	31	Glioblastoma	University	Single	Family (mother)
12	Male	64	Colon cancer	Elementary	Married	Family (wife)
13	Male	52	Laryngeal cancer	High	Divorced	Family (daughter)

the medical staff treating them and therefore understood the nature of their disease when anti-cancer therapy was discontinued. All the patients were conscious except one. However, despite their many distressing symptoms, all the interviewed subjects maintained the desire to sustain their lives and did not abandon the hope of prolonging their lives. There were various reasons underlying this desire, such as worries about their family members, self-reported alleviation of symptoms, fear of disease exacerbation caused by giving up hope, and vague expectations about new drugs.

"Because our kids are still young, I haven't thought that I will die soon. I just keep thinking that I need to exercise diligently ...," said one patient. "Even though there's no medication for me yet ... I am not just waiting, but expecting that it will come out soon ... Above all, I am able to eat a meal ... so I would like to retain hope that I can wait for a new drug to be made available ...," said another patient. Another patient did not desire to be cured per se, but rather to prolong their lifespan, saying, "The reason why I do not talk to anyone about my situation is that I need to have a little hope ... Ah ... I just would like to have a little hope that I can overcome it ... I do not expect my disease to be cured, but extended."

Wishing for Peaceful Death. The patients and their caregivers also expressed the strong desire for the patients to experience a peaceful death. The chief complaints of the patients included general lethargy, dyspnea, and insomnia, accompanied by anxiety about other symptoms that may occur in the future. The perceived need for a painless and peaceful death was proportionate to the level of such anxiety.

Patient: "If I am destined to die, please let me die without suffering."

Caregiver: "If he/she faces an inevitable death, I hope he/she dies peacefully ... (crying)."

Difficulties in Open Communication Among Family Members Regarding the Prognosis. One patient's family members expressed the difficulties they experienced in having heart-to-heart conversations with the patient regarding death. When the patient said that they did not expect to live longer, their family members encouraged the patient to maintain a hopeful outlook rather than consoling the patient. In the face of death, it was hard for the patient and their family members to honestly express their thoughts or what they needed to hear because of worries regarding the psychological impact that talking about death might have on one another.

In addition, because most caregivers were unaware of the perceptions or attitudes of the patients

regarding death, they were reluctant to converse about this topic with the patients. Thus, preferences surrounding the process of death and the discontinuation of treatment were rarely if ever discussed. Some of the caregivers who answered that they were prepared for a patient's death had engaged in conversations that were mainly focused on practical issues, such as funeral arrangements or how to tie up a patient's estate after their death.

With respect to the use of painkillers for cancer-related pain, it was commonly relayed that "if you [a cancer patient] feel any pain, ask for painkillers" or that "pain killers are needed to reduce pain." However, worsening pain signals a worsening illness, and this can lead to the fear of death. Thus, cancer patients did not fully reveal their worsening symptoms to the medical staff providing care.

Perceptions of PS

Lack of Knowledge Regarding PS. The enrolled patients and their caregivers were unaware of PS. After PS was explained to them, caregivers stated that they would wake the patients up if their consciousness was degraded for a long period because they would have anxiety about the condition of the patients. In addition, while the patients' levels of pain might have been made bearable with PS, their caregivers made the following statements: "[the patient] seems to not sleep well at night. [the patient] keeps waking up after brief sleep ...," "[the patient] feels frustrated because he/she could not walk due to swelling in his/her legs. In addition to sickness, [the patient] feels confined ... [the patient] usually sleeps a little while sitting." One patient stated, "I am out of breath ... I cannot wish for anything more than walking without difficulty breathing." However, they opined that these symptoms could not be controlled.

The Need for the Effects of PS. The subjects who did not experience pain relief after the use of painkillers, even at an increased dosage, or who experienced other symptoms, such as dyspnea, vomiting, and sleep disorders, sought alternative therapies to mitigate these symptoms.

One patient asserted, "I would like to live without pain until the day I die, but I have no idea [how to reduce the pain] except for painkillers. But, painkillers cause me many side effects" Another patient stated, "In addition to pain, I am so out of breath that I'm having continuously interrupted sleep day and night. So, I am lethargic ... not eating ... not sleeping"

Individualized Expectations Regarding the Effects of PS. There were differences in the expectations of the patients and their family members regarding the level of PS that was needed. Some patients and their family

members expressed that the level of PS administered should be determined based on the requests of the patients and their family members if they were in a condition that necessitated PS. They feared that heavy and/or prolonged sedation could result in the patient experiencing distress or death without regaining consciousness. One patient expressed a need “to be conscious and able to react.” In contrast, other patients desired a level of PS that would enable them to not feel any suffering at all. Overall, various levels of PS were sought by the patients.

Timing of Decision-Making Regarding PS and the Decision-Makers

The Timing of Decision-Making Regarding PS. Most patients and their family members stated that the timing for deciding on the use of PS should be before the suffering caused by terminal cancer becomes too great. This is because the suffering from their illness could lead to the degradation of their consciousness and lethargy, possibly preventing patients from making reasonable decisions after listening to explanations about PS. However, a few of the patients and their family members responded that they could determine the need for PS even while they were in distress because of the uncertainty of their prognosis.

The Decision-Maker for PS. Opinions on who should make decisions regarding therapies, including PS, varied. Some thought it should be a patient’s decision, whereas others believed that it might be difficult for a patient to make a reasonable decision because they would hold onto wishful hope. Therefore, some family members said that they were better equipped to make the decision. A minority of the patients’ family members thought that a physician should determine whether the patient should receive PS. For those asserting that the patient should decide on their own therapies, the reasons provided were either that the patient has always been their own decision-maker or that the patient and their family members had been continuously informed of the necessity for the patient to make treatment-related decisions. For those who answered that a physician should be the decision-maker, they expressed that the physician’s expertise provided a sense of trust in the decision.

Discussion

The present study investigated the demand for PS and the perceptions surrounding decision-making regarding PS through in-depth interviews with 13 patients suffering from terminal cancer and their family members. The sample size was determined after achieving content saturation. To our knowledge, this

is the first study to investigate such perceptions in this demographic. Brajtman et al.¹⁸ conducted a qualitative study that included an assessment of PS that was targeted at bereaved families, but the subject of the research was not about PS per se but rather the experiences and perceptions of caregivers about indications for refractory symptoms at the moment of death.

The terminally ill cancer patients in this study experienced various symptoms, including pain, lower extremity edema, general weakness, bleeding, dyspnea, loss of appetite, ascites, and sleep disorders. They expressed a wish to die peacefully as their suffering increased. However, when their suffering was even slightly relieved, they showed ambivalence, continuously holding onto hope for a longer life. These results are consistent with those of previous reports demonstrating that although terminally ill cancer patients and their family members understand the nature of the illness, they retain an ongoing hope for life.^{21,22} This hope for improvement can be interpreted not as denial of death itself, but rather as a psychological defense mechanism that overrides suffering and the uncertainties that exist surrounding the process of death.^{22,23} Thus, when discussing issues such as prognoses or PS with dying patients and their caregivers, it is suggested that appropriate communication techniques are used and that hope is maintained through various means instead of rejecting any optimistic sentiments.^{24,25} Back et al.^{26,27} asserted that a “hope for the best, prepare for the worst” communication style would help patients and caregivers redefine hope and cope with the realities of the situation. In this case, the appropriate time for discussing PS would be when the cognitive function of patients is still intact.

In addition, the enrolled, terminally ill cancer patients and their family members considered that painlessness constituted a comfortable condition and regarded other symptoms, such as sleep disorders and dyspnea, as uncontrollable symptoms. Thus, more aggressive interventions should be provided to mitigate symptoms that are difficult to control in terminally ill cancer patients. In particular, this appears to be necessary for such patients to feel more comfortable using PS.

The current results show that most patients and caregivers in our study seemed to have no prior knowledge of PS. It seemed that PS had not been appropriately explained due to negative perceptions or ignorance about PS by the patients’ medical teams. Indeed, a previous study reported that negative perceptions of PS by medical teams was the most limiting factor in its implementation.²⁸ However, 78%–93% of caregivers who experienced PS were satisfied with its use, and 88% of them stated that PS helped to relieve the suffering of the patients under their care.

Therefore, training medical teams regarding the use of PS should be prioritized in the future.²⁹

Various opinions exist regarding the need for PS, the extent of consciousness degradation caused by PS, and the process, including the timing, of decision-making regarding PS. Morita et al.³⁰ surveyed a general population regarding their preferences surrounding PS and found that 86% of respondents would like to try PS for alleviating refractory symptoms; however, 72% expressed resistance against continuous PS. In the present study, many patients and family members also had fears surrounding the use of heavy or prolonged PS, including that it could lead to death without regaining consciousness. This result suggests that appropriate information on PS must be provided and that in-depth discussions with caregivers about the level of PS needed must occur. Several guidelines also recommend the implementation of intermittent or light medical sedation before the initiation of continuous sedation.³¹ We previously reported that intermittent PS could serve as a possible solution to patients with ambivalent feeling about its use.³² Further studies on the optimal timing and sedation levels of PS for patients are warranted.

Regarding the decision to use PS, most of the interviewees thought that a patient should be the primary decision-maker and that the decision should be made while the patient could maintain a state of consciousness and before a decline in cognitive function. However, we identified communication difficulties between caregivers and patients regarding disease prognosis. These results imply that open communication regarding a patient's prognosis is needed between medical teams and patients.

The use of PS should be determined at the time that a diagnosis of terminal cancer is explained and a treatment prognosis is made. This is because patients in the terminal stage of cancer might not be capable of making reasonable decisions on therapeutic interventions due to severe suffering, and family members may have negative impressions about PS due to their fears regarding the patient's death. In recent years, this topic has been increasingly discussed in the Republic of Korea as a consensus for and guidelines about advance medical directives are being developed.^{33,34} In the future, after a full explanation of PS is provided to patients by their medical team, the inclusion of PS in advance medical directives may also be used to relieve the suffering of terminally ill cancer patients.

If a decision on the implementation of PS is included in an advance medical directive, the psychological pressure on caregivers may be reduced.²⁹ In addition, although reflecting a patient's intention is the most important consideration when implementing PS, if a discussion regarding PS occurs too late, it is quite difficult to determine a patient's intention

due to a decrease in their cognitive function. Thus, additional studies regarding the timing of this implementation are still needed.

There are some limitations to this study. First, controversy surrounding the trustworthiness of our data may exist. Although data saturation is a credible concept, each life is unique and in this sense, data are never truly saturated as there will always be new things to discover.³⁵ Second, the applicability of this study cannot be determined because of the limited demographic nature of patients and caregivers. Further studies that include the influence of characteristics such as health care delivery systems, relationships of doctors, patients, and caregivers, and cultural factors are warranted to assess the generalizability of our findings.

In conclusion, terminally ill cancer patients and their caregivers expressed ambivalent desires, simultaneously hoping to prolong life and to experience a peaceful death. Improvements in communication among physicians, patients, and caregivers about prognoses and the implementation of PS are needed.

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The authors declare that there is no conflict of interest.

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