


Timely Identification of Patients With Cancer and Family Caregivers in Need of End-of-Life Discussions by Home-Visit Nurses in Japan: A Qualitative Descriptive Study

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日本の訪問看護師によるがん患者と家族介護者に対する「終末期の話し合い」の最適なタイミングの特定：質的記述的研究

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Abstract

End-of-life (EOL) discussions for patients with cancer are a key factor of successful EOL care; however, identifying the optimal timing for these discussions in Japanese home-care settings is difficult. To identify the time at which patients with cancer and their caregivers need EOL discussions, we explored when home-visit nurses start EOL discussions. We interviewed 23 home-visit nurses and analyzed the data using qualitative content analysis. Three themes were derived from the analysis. Participants identified the timing of EOL discussions as being sensitive to patients' changing health and care needs (increases in patient's total pain), changes in the family caregiver's physical or mental condition through daily care (increases in family caregiver distress), and the EOL process that patients follow (trajectory of disease). Developing a tool or in-service educational program that will enable inexperienced or new graduate home-visit nurses to implement EOL discussions at appropriate times is necessary.

Keywords

end-of-life discussions, home-visit nurses, cancer, timely identification, qualitative descriptive study, Japan

概要

がん患者に対する「終末期の話し合い」は、終末期医療を成功させるために重要な要素であるが、日本の在宅医療の現場において、終末期の話し合いの最適なタイミングを特定することは困難である。そこで、がん患者やその家族介護者がどのようなタイミングで終末期の話し合いを必要としているのかを明らかにするために、訪問看護師が終末期の話し合いを開始するタイミングを調査した。23名の訪問看護師に面接を実施し、質的内容分析を用いてデータを分析した。その結果、3つのテーマが導かれた。訪問看護師は、患者の健康状態やケアニーズの変化（患者の全人的苦痛の増加）、日々のケアによる家族介護者の心身の状態の変化（家族介護者の苦痛の増加）、患者が辿る終末期のプロセス（疾患の軌跡）を踏まえて、終末期の話し合いのタイミングを特定していた。今後、経験の浅い訪問看護師や新卒の訪問看護師が適切なタイミングで終末期の話し合いを実施できるようツールおよび現任教育プログラムの開発が必要である。

キーワード

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Cancer remains the second leading cause of death worldwide, with an estimated 9.6 million deaths in 2018 (World Health Organization, 2022). In Japan, it is the leading cause of death, with 378,385 deaths in 2020 (Portal Site of Official Statistics of Japan, e-Stat., 2020). In this context, discussions regarding end-of-life (EOL) care between patients with cancer, family caregivers, and healthcare providers play a key role in successful EOL care. EOL discussions are characterized by giving patients and caregivers the opportunity to examine their goals and expectations for the medical care that they want to receive while approaching the patient's death (Mack et al., 2012; Wright et al., 2008). Discussions should be implemented when patients are approaching inevitable death to identify how and where to spend their remaining life and should be repeated continuously. Studies have indicated that, for patients with advanced cancer, high-quality EOL discussions are associated with less aggressive medical care (Wright et al., 2008), greater use of hospice care at EOL through early EOL discussions (Mack et al., 2012), improved patient quality of death, and reduced depression and complicated grief in the bereaved family (Yamaguchi et al., 2017).

According to a Japanese government survey, 54.6% of patients with terminal cancer wished to die at home (Ministry of Health, Labour and Welfare, 2017). However, the trend of death in Japan from 1998 to 2017 showed a high percentage of deaths in hospitals (over 80%), as compared to a low percentage of deaths at home, ranging from 12.2% to 15.9%, with 12.3% in 2019 (Koyama et al., 2020; Portal Site of Official Statistics of Japan, e-Stat., 2020). A systematic review highlighted that the incongruence between preferred and actual death places seems to be substantial worldwide (Nilsson et al., 2017). A previous systematic review indicated that EOL care at home increases the possibility of death at home compared to usual care and slightly improved patient satisfaction (Shepperd et al., 2021). Considering these results and the increase in the number of cancer deaths and the growing need for care at home, we believe that home-visit nurses, who understand both the patients' medical and lifestyle needs, provide direct care at home on a daily basis and listen to patients' feelings and wishes during their daily care, take the initiative to provide EOL care in accordance with the patient's wishes in collaboration with physicians and caregivers, and play a critical role in communicating with terminal patients with cancer.

Home-visit nurses visit patients' homes alone to provide care, including basic nursing care (bathing, toileting, and eating), skilled nursing care (physical assessment, injection, and pressure ulcer care), and EOL care in collaboration with primary physicians and health and social care professionals. Although a previous study has shown that a higher percentage of home-visit nurses discussed EOL decisions with patients compared with hospital nurses (Joren et al., 2021), another reported that hospital nurses were more willing to engage in EOL discussions compared with home-visit nurses because of differences in work settings and level of nursing education (Albers et al., 2014). Furthermore, another study reported that

new graduate home-visit nurses experienced difficulties in understanding and providing care based on the patient's needs (Akiyama & Fukuyama, 2020), and that working at a home-visit nurse station was not a realistic option for them because it required specialized and extensive experience (Abiodun et al., 2019; van Iersel et al., 2016). In other words, new graduate home-visit nurses, who face difficulties in assessing the patient's needs, and inexperienced home-visit nurses find it difficult to determine when to implement EOL discussions that are required by the patient and family; thus, establishing a base from which to determine the appropriate timing to broach the EOL discussions is necessary.

In a previous study on the timing of EOL discussions for patients with cancer, those who had undergone EOL discussions prior to admission were likely to receive higher quality EOL care (Mori et al., 2013), and patients with ovarian cancer who had an EOL discussion 30 days before death were significantly less likely to be admitted to acute care facilities (Lopez-Acevedo et al., 2013). In addition, regarding the outcomes of inappropriately timed EOL discussions among hospitalized cancer patients, 79% of patients had decision-making capacity at admission, but 40% of patients lost decision-making capacity immediately prior to the EOL discussion, requiring a proxy to make all care decisions (Zaros et al., 2013). However, a systematic review suggested that patients and caregivers had mixed feelings about the best timing; many people preferred to postpone discussions until they perceived them to be clinically relevant because they can be turbulent and upsetting, regardless of their many benefits (Hall et al., 2019; Miyashita et al., 2020). Conversely, some bereaved families felt that the timing of explanations about impending death was slow and inappropriate (Mori, Morita, et al., 2018; Yamaguchi et al., 2021), and that delayed prompting for action to prepare for death can increase depression and complicated grief in bereaved families (Mori, Yoshida, et al., 2018). Considering this context, previous research about the appropriate timing for initiating or conducting EOL discussions is mixed and unclear; moreover, a systematic review of EOL discussions and interventions concluded that further research is required to establish the optimal timing of interventions in healthcare provider-led EOL discussions (Jung & Matthews, 2021).

This study explores when home-visit nurses determine that EOL discussions are necessary for patients and families, thereby helping nurses identify those patients and families in need of EOL care discussions and consider appropriate timing for their implementation. We believe that this study could add basic knowledge toward developing a tool or in-service educational program that will enable inexperienced or new graduate home-visit nurses to implement EOL discussions at appropriate times.

Research Purpose

This study aims to describe and gain insight into EOL discussions for home-visit nurses to identify the appropriate time at

Table 1. List of Questions.

1	When did you decide to initiate and implement EOL discussions for terminally ill patients with cancer and/or their family caregivers?
2	How did you initiate and implement EOL discussions for patients with cancer and/or their family caregivers?
3	Why did you implement EOL discussions at that time?
4	What has happened to your patients and/or their family caregivers before and after EOL discussions?

which patients with cancer and families need these discussions in Japan. This study defines EOL discussions as “repeated discussions by home-visit nurses with patients and their family caregivers regarding the treatment and care they would like to receive, where and how they would like to spend their time, and their chosen place of death in the terminal stage.”

Methods

Study Design

A qualitative descriptive design, as described by Sandelowski (2000), was used for this study. We chose this method for two reasons: First, we aimed to explore the events based on the exact description of the situations that caused nurses to start and implement EOL discussions. Second, we aimed to summarize the data with in-depth, everyday, fact-based language that facilitates the understanding of these situations (Colorafi & Evans, 2016; Sandelowski, 2000).

Sample and Recruitment

Twenty-three home-visit nurses in Japan were selected using a snowball sampling strategy because of the inclusion criterion that study participants had to have experience in conducting EOL discussions for terminally ill patients with cancer. We also considered a minimum of 6 months of home-visit nursing experience a compulsory condition for inclusion in this study. Although the interviewer and several participants were acquainted with each other, they had never had a conversation about this research topic before. The first author informed the first home-visit nurse who was interviewed about their requirements and asked them to refer the subsequent participants via email or telephone. This study included participants from 14 home-visit nursing agencies in Japan, having prior experience with EOL discussions for terminally ill patients with cancer and at least 6 months of experience working as a home-visit nurse.

Data Collection

We collected data from February 2020 to June 2021. Participants’ basic demographic information and the clinical information of cancer cases at baseline were obtained through a short interview. The data for analysis were collected through semi-structured interviews with the 23 home-visit nurses. Interviews were conducted online or face-to-face, once for each participant. Participants were interviewed in

quiet locations at their home-visit nursing agencies, as was convenient to them. Interviews lasted between 42 and 78 min. We decided to collect data from 23 home-visit nurses for two reasons: the unlikelihood of additional data from other nurses changing the results and time constraints.

Participants were asked to freely describe their perceptions and experiences. The interview questions were open-ended and based on the researchers’ clinical experience (Table 1). During the interviews, additional notes were taken on participants’ facial expressions, speech, and silence, which aided in the analysis. All the interviews were recorded with an IC recorder and transcribed verbatim. We hired a professional transcription company to perform the transcriptions and signed a non-disclosure agreement with them.

Data Analysis

Data analysis and collection were conducted concurrently. We added the participants’ facial expressions, speech, and silences noted during the interview into the transcriptions of the interviews prior to data analysis. The data were analyzed using conventional qualitative content analysis (Hsieh & Shannon, 2005). First, the transcriptions of the interviews were read thoroughly several times to obtain a sense of the whole dataset. Second, these texts were divided into condensed meaning units, which were then labeled with codes. The codes were sorted into 15 categories and seven sub-themes based on comparisons regarding their similarities and differences. Finally, three themes were formulated regarding the expression of the latent content of the text.

The analyses were conducted in Japanese, which were translated into English when writing this article. The professional translator’s and editor’s corrections were re-examined by the authors to ensure an adequate English-Japanese fit.

Study Rigor

To achieve rigor in this qualitative research, we followed the framework proposed by Lincoln and Guba (1985), which is related to credibility, transferability, dependability, and confirmability. Credibility was achieved through prolonged engagement in the research field. All authors were familiar with the topic of this study because the first and second authors had worked as home-visit nurses; the first author, who was the interviewer, and the third author had extensive interviewing experience prior to this research. We sought to eliminate preconceived notions by putting their own experiences in parentheses during the interview and analysis processes to lessen bias in interpreting them in light of our

experiences. The interviewer tried to maintain an open, genial attitude to encourage participants to talk, and to redirect the interview when a participant's statements deviated significantly from the question. These interviewing skills and attitudes were developed by training through workshops on qualitative research during the master's and doctoral programs. Interview data were collected using data triangulation by observing and noting participants' facial expressions, speech, and silence during the interview. To improve transferability, we added descriptions that explained background information about the patient, family, and other details of the circumstances leading to EOL discussions as much as possible. To promote dependability and confirmability, several meetings among researchers were held to develop codes, categories, and themes after the first author coded the data. Any disagreements were discussed until a consensus was reached. The coding process was documented in an Excel file to allow tracking of the analysis and provide an overview of the process.

Ethical Considerations

This study was approved by the ethics committee of Tokyo University of Technology (no. E19HS-019) with which the first author was affiliated. All participants provided written informed consent. They were informed that participation in the study was voluntary, and they could refuse to participate or withdraw from the study at any time without any negative impact. Before the interview, the interviewer assured the participant that the interview could be interrupted immediately if they felt distressed while recalling their experiences. Additionally, close attention was paid to the participants' mental changes before and after the interview. To protect their identities, any audio-recorded and all transcribed interview data were anonymized by substituting numbers for individuals' names. The data were stored in password-protected files.

Results

Participant Characteristics

We interviewed 23 home-visit nurses working at 14 home-visiting agencies (13 in Tokyo and 1 in Hiroshima). The participants included 21 women and two men (nine administrators, four oncology-certified nurse specialists, three palliative clinical specialists, and one home-care clinical specialist), whose ages ranged from 20 to 59 years. The mean of total years of nursing experience was 17.7, and that of home-visit nursing experience was 7.0.

Characteristics of Patients with Cancer and their Family Caregivers

To contextualize the nurses' experiences, we gathered information about the patients in their narratives. Patients included 14 men and 13 women, whose ages ranged from 30s to 100s.

Twenty-five lived with family caregivers (13 spouses, 10 children, 2 parents). The patients' cancer sites varied and included colon ($n=5$), breast ($n=4$), gastric ($n=4$), lung ($n=2$), brain ($n=2$), head and neck ($n=2$), liver ($n=2$), gallbladder and pancreas ($n=1$), and urinary tract ($n=2$) cancer, as well as four other types of cancer. The most common places of death represented in the nurses' narratives were home ($n=15$), hospice or hospital ($n=6$), and nursing homes ($n=2$). Four deaths occurred in a variety of other locations.

Timely Identification: Need for EOL Discussions by Home-Visit Nurses

Three themes were identified to describe the nurses' experiences of identifying the time to start EOL discussions: disease trajectory, increases in patient's total pain, and increases in family caregiver distress.

Trajectory of Disease. Changes associated with the trajectory of the disease prompted nurses to begin EOL discussions. They often began when a patient was discharged to start palliative care at home, when previous treatments and care services were no longer effective, and when a sudden change in medical condition was expected, as addressed below.

Change to Palliative-Oriented Care. In many cases, cancer patients are given aggressive treatments such as chemotherapy until just before their death. Therefore, many patients transition to home care and begin home nursing care when chemotherapy is no longer effective or when they change to palliative care, which is when EOL discussions are implemented. In many cases, patients also change the type of medical or nursing care services they have been receiving according to their medical conditions, and this often indicates the appropriate time for an EOL discussion with regard to the question: "How do you want to live at the end of your life?" The following quotations from the interview data illustrate this subtheme:

When we (home-visit nurses) began home care, we tried to ask the patient what they want us to do. The patient (with breast cancer) said that she wanted to take another treatment even if she had lung metastasis and complained that she wanted to do something about her breathlessness . . . We made sure that what we were offering was not implicitly aimed at treatment, but rather "let us make symptom relief the goal for now." [Nurse #20]

A patient (diagnosed with colon cancer) tended to lie in bed due to blisters and pain in his feet. This change in his condition triggered a meeting (with providers of medical and nursing care services and family members) to discuss the situation. I felt that at this time, when we were reviewing services, it was necessary to discuss EOL based on the prognosis. [Nurse #8]

When Previous Treatments and Care Are No Longer Effective. Patients with cancer can suddenly develop a variety of physical symptoms weeks or days before they die, requiring assessment

of their physical and mental care needs, as well as various medical procedures. Therefore, when emergency visits to the hospital, emergency hospitalizations, and requests from patients and their families for urgent medical treatment-related calls and emergency visits increase, the nurses identify that it is the right time to start discussing EOL care, as seen in the following quotes.

Emergency hospitalizations and emergency visits increased, making it difficult for patients (diagnosed with Glioma) to attend (regular) outpatient visits . . . so, I recommended starting doctors' visits and talked about where and how to spend (the last hours of life) simultaneously. [Nurse #5]

The tumor had self-destructed (i.e., the tumor was getting worse), and once a day was no longer sufficient to treat it. So with this sudden change, I started to visit twice a day . . . I thought it was time to have a discussion [about the patient's future]. [Nurse #12]

When a Sudden Change in Medical Condition is Expected. Because patients with cancer experience a variety of physical symptoms as they approach death, healthcare providers make rough estimates of whether they will die on a monthly or weekly basis. During this time, a doctor must explain that the patient has a severe medical condition and any changes in treatment or care to alleviate symptoms, as well as the reason for such changes. Therefore, the participants indicated that it is necessary to conduct EOL discussions with more in-depth content during this time, as illustrated below.

When he (the patient) was discharged from the hospital, we were informed that his prognosis had been explained to him as "monthly," so I began (discussing EOL care) with "How did the doctor tell you?" [Nurse #4]

I contacted the children and told them that the patient's condition (colon cancer) was getting much worse, so it would not be surprising if it suddenly changed at any time; I asked them how they would like end-of-life care conducted and the place where the patient would be cared for. [Nurse #15]

He (the patient with colon cancer) was told by the doctor something quite severe, such as "The treatment doesn't work anymore," or "It would be difficult to live until spring;" so, I thought this was the right time (to discuss EOL care). [Nurse #19]

Increases in Patient's Total Pain. Significant increases in patients' total pain, such as physical, emotional, and spiritual distress, prompted home-visit nurses to begin EOL discussions, as illustrated below.

When the Patient's Physical Distress is Increasing. When irreversible physical symptoms appeared or the patients spoke about "my prognosis," the nurses again confirmed with the patients where and how they want to die considering

the future expected changes in their physical symptoms. This is explained by an interviewee [Nurse #17]: "Over the last month or two, the patient's (with stomach cancer) appetite dropped again, and she couldn't eat. We thought that it would be difficult to recover. So, I realized that it is necessary to talk about what's ahead." Furthermore, the following quote outlines this theme.

When a patient with increasing physical pain (diagnosed with malignant lymphoma) said without a sense of sadness, "I want to die soon (known as omukae)," I thought it was a good opportunity to talk about death directly and ask him exactly what he is thinking about. [Nurse #11]

When the Patient's Psychological and Existential Distress Becomes Apparent. When the patients themselves expressed their awareness of their mortality, or when they showed existential distress regarding the meaning of life, the nurses encouraged them to express their thoughts and talked to them so that they would view death as a reality. The following quotations from the interview data illustrate this subtheme.

After the situation frequently worsened, he (the patient with oral cancer) would say, "Why do I have to go through this at my age? I really want to die because it is meaningless to live like this, being a nuisance to others and being taken care of by others. How can I die? But I was also told that I cannot kill myself . . ." and that kind of thing, while holding my hand a lot. It was at that time that I talked about death. [Nurse #22]

A patient (with colon cancer) was gradually becoming less able to move and was out of breath when she spoke, and I thought she was asking me to understand her feelings without having to say them. So, I indirectly asked her, "It's nice to be home, isn't it?" to see her reaction. I think this kind of thing can only be handled by an experienced nurse. [Nurse #2]

Increases in Family Caregiver Distress. Home-visit nurses determined that when family caregivers expressed difficulty accepting the patient's death or complained about the burden of caring for the patient, it was the appropriate time to implement EOL discussions, as illustrated in the subthemes below.

When Family Caregivers had Difficulty Coping with the Patient's Death. Many patients with cancer are told that death will come in the not-too-distant future, whether in the hospital or as an outpatient, when aggressive treatment is discontinued. Although both patients and their families know that death is inevitable, in many cases, they do not have an image of what physical symptoms will appear a few weeks beforehand. Consequently, patients and families are often distressed by the physical and mental symptoms patients experience after beginning home care, often shaking their resolve and causing them to feel lost. Nurses reported cases in which patients and family members had different intentions or disagreed on matters such as where to spend patients'

final days, where to die, and whether to perform cardiopulmonary resuscitation. In these situations, considering the feelings of the patient and family, nurses were prompted to initiate EOL discussions, as illustrated below.

The patient's eldest daughter wanted to take care of her mother (with liver cancer) at home, but the second daughter wanted to hospitalize her for treatment. Even among family members, there were differences in opinions, so (discussions) were felt to be necessary. [Nurse #9]

He (the patient with colon cancer) gradually became weaker and less able to move, so I was concerned about how much support his family would be able to provide at home. In fact, his wife said, "It is going to get a little tougher for me to do things on my own." . . . When we actually started home nursing, the wife and son (who lived with the patient) told us, "I don't know how he's going to turn out, but if he becomes bedridden, it would be very difficult to see him at home." However, the patient had no intention to stay in the hospital. That is when I identified a gap [between the patient and family's wishes], and I thought a discussion was necessary. [Nurse #21]

When the Family Caregiver's Burden has Increased. Patients with cancer can experience loss of consciousness, cold extremities, irregular breathing, or terminal delirium as they approach death. Family caregivers often experience psychological pain from seeing such changes. Moreover, caregivers also experience a physical burden. Therefore, participants explained they were attentive to caregivers' physical and mental condition and identified when it was necessary to implement EOL discussions to encourage caregivers to prepare for EOL care, as illustrated below.

I think it is the correct timing when a family member asks about a patient's condition. When they ask, "He (patient) seems to be in so much pain, should he go to the hospital? What should I do?" and I ask back, "What do you want?" Then, when the family asks questions, such as supplementary explanations about medical procedures and care the patient can receive if he goes to the hospital, it is easier to facilitate (the EOL discussion). [Nurse #2]

In describing her experiences related to caring for a patient with malignant lymphoma, a nurse stated, "His wife was a very devoted person who was by his side 24 hours a day . . . When she (his wife) became tired, his condition deteriorated as well, and I discussed the future at that time." [Nurse #11]

Discussion

Main Findings

To provide quality EOL care, it is essential to initiate or conduct discussions at appropriate times for patients and their family caregivers. The results of this study suggest that home-visit nurses identify the timing of the EOL discussions while being sensitive to patients' changing health and care

needs (increases in patient's total pain), changes in the family caregiver's physical or mental condition through daily care (increases in family caregiver distress), and the EOL process that patients with cancer follow (trajectory of disease). This study is one of the few to examine home-visit nurses' timing of EOL discussions for patients with cancer and their family caregivers in Japan. While there is no agreement on when to initiate or conduct EOL discussions in international clinical practice, our findings, considered in the context of the wider international literature on this topic, provide possible considerations in making decisions about the timing and approach to EOL discussions, which are the foundation of EOL care. In particular, we believe that the timing of EOL discussions, which home-visit nurses grasp by being sensitive to changes in the patients with cancer and their family caregivers while anticipating the clinical course of cancer in the home-care setting, is a useful insight into other clinical settings where EOL care is provided.

First, data show that the average time from initiating home nursing care to death is 3.32 months for patients with cancer, compared to 11.95 months for patients without cancer in Japan (Ministry of Health, Labour and Welfare, 2011). Foreign research showed that participants in the EOL home-care group only spent 2 weeks at home prior to death (Grande et al., 1999). Previous studies have suggested that some bereaved families felt that the timing of explanations about impending death was slow and inappropriate in Asian countries (Mori, Morita, et al., 2018; Yamaguchi et al., 2021), and that delayed prompting for action to prepare for death can increase depression and complicated grief in bereaved families (Mori, Yoshida, et al., 2018). However, research indicates that patients with cancer who had EOL discussions before the last month of life were less likely to receive aggressive care and more likely to receive hospice care (Mack et al., 2012). We believe that these results may support our findings that home-visit nurses paid special attention to changes associated with the trajectory of the disease that indicate imminent death to determine the need for EOL discussions, which may lead to death at home. Thus, due to the short period of time between initiating home care and patients' deaths, we believe that accurately assessing the timing of communication about EOL issues between patients and their family caregivers and encouraging them to prepare for death quickly is an important role for home-visit nurses.

According to National Institute for Health and Care Excellence (2019) guidelines, the appropriate time for EOL discussions cannot be uniformly determined for organ-failure diseases whose trajectory is hard to predict, such as heart failure or chronic obstructive pulmonary disease, and cancer, the trajectory of which can be predicted. This is because patients with organ-failure diseases typically experience periods of deterioration and recovery over the course of years, whereas patients with cancer experience weight loss and self-care disability in their last 2 months (Lynn, 2001). Thus, EOL discussion is needed at significant milestones in

the disease trajectory of a patient with organ failure until death within years (Schichtel et al., 2020). Among cancers, glioblastoma patients should begin decision-making about future care early, including EOL, because they experience progressive cognitive dysfunction (Fritz et al., 2016). It can be inferred that the timing of EOL discussions should be considered depending on the cancer type.

Second, previous research indicated that a higher percentage of home-visit nurses stated that they provided care in the physical and psychological domains and discussed EOL decisions with patients than hospital nurses (Joren et al., 2021). These results may support our findings that home-visit nurses assess patients' physical and mental care needs in conjunction with determining the timing of EOL discussions. We believe that identification of this stage requires the unique observational skills of home-visit nurses because, unlike hospitals, home care does not utilize extensive testing equipment. For example, blood data and other useful material can be used to assess the progress of a patient's condition, and in a hospital, the results of blood tests can be checked immediately by a healthcare professional; in-home care, the results are submitted to a testing center and received several days later. Therefore, a home-visit nurse will utilize all five senses to carefully collect data on the patient's physical state, observe the degree to which the patient's condition interferes with their daily life, and note any changes between the last and current visit. Additionally, by asking family members and nursing staff about the patient's condition in the absence of the home-visit nurse, vital information on the progress of the patient's illness can often be obtained. Based on this multifaceted information, nurses can identify the stage at which death is approaching for the patient and, therefore, determine whether an EOL discussion is necessary.

In addition, it has been pointed out that although smaller percentages of nurses in both home care and hospitals provided care in the social and spiritual care domains, relatively more home-visit nurses provided care in these domains than hospital nurses (Joren et al., 2021). This was similar to our findings that home-visit nurses paid attention to patients' existential distress. We believe this may be because feeling more secure at home and being able to discuss and talk about existential questions influences the provision of spiritual and social care (Joren et al., 2021). Participants in our study included those with highly developed communication skills, such as certified nurse specialists and clinical specialists, allowing them to notice existential distress, which is an intangible symptom.

Third, the importance of strengthening cooperation between the medical, nursing, and welfare professions, as well as community-based complete medical care should be considered because population aging is accelerating rapidly worldwide. While a hierarchical relationship between general practitioners and nurses has a negative impact on the process of communication about palliative care (Mahmood-Yousuf et al., 2008), a Japanese study revealed that a

multidisciplinary EOL education intervention program to promote face-to-face collaboration and smooth communication among medical and social service professionals had a positive effect on inter-professional collaboration between home-visit nurses and welfare workers (Fukui et al., 2019). Considering these results, we believe that our participants did not mention the difficulties of handling the EOL discussions because they maintained a good relationship and collaboration with doctors and other health and social care providers through daily care or meetings.

Fourth, Japan's cultural context is such that family-centered decision-making is considered. A systematic review indicated that given the influence of sociocultural beliefs at the end of life, the emphasis on personal autonomy, which is fundamental to the Western concept, may not be equally valued in all cultures in the context of decision-making for EOL (Hall et al., 2019). In fact, an old study exploring possible differences in the scope of EOL decisions indicated a high prevalence of entrusting all decisions to the family (known as *omakase*) compared with the USA and Germany (Voltz et al., 1998). However, a recent systematic review indicated that 39% to 90% of Asian patients, including those in Japan, were willing to encourage discussion about their disease and prognosis (Martina et al., 2021). This suggests a shift from entrusting all decisions to the family to more with family or more autonomous decision-making, perhaps due to modernization and globalization. These findings may support that home-visit nurses considered a patient's own preferences and family caregivers' readiness to be equally important; hence, our results may be transferable to the Asian region, which is seeking a common understanding with families in EOL care. The second impact involves the communication style preferred by the Japanese. It is pointed out that consideration should be given to the traditional idea of wanting to know the truth through indirect, euphemistic, and nonverbal means (known as *ishindenshin*) (Yamaguchi et al., 2021). Especially in situations when sensitive topics such as EOL care are being handled, this may support that home-visit nurses infer patients' needs and utilize it in EOL care through daily care, even if they do not explicitly ask about the patient's needs in our results.

Implications for Practice

Our findings suggest that home-visit nurses identify the timing of the EOL discussions while being sensitive to patients' changing health and care needs (increases in patient's total pain), changes in the family caregiver's physical or mental condition through daily care (increases in family caregiver distress), and the EOL process that patients with cancer follow (trajectory of disease). We believe that these findings will contribute to the implementation of EOL discussions at appropriate times to provide quality EOL care and may lead to deaths at home. Moreover, considering previous findings that nurses who have received basic or continuing education

in EOL in the past 2 years are more involved in medical EOL decision-making than those who have not (Albers et al., 2014), our findings may contribute to the development of a tool for assessing the appropriate timing of EOL discussions. Additionally, these findings can potentially be utilized within educational programs for not only inexperienced or new graduate home-visit nurses but also in-service education for home-visit nurses.

Limitations of this Study

First, time constraints were one factor in the decision to complete data collection, due to which insufficient consideration was given to data saturation. Second, most participants belonged to home nursing agencies in Tokyo. Thus, there can be differences in nurses' experiences with EOL discussions in urban areas, where access to healthcare facilities is easier than in rural areas. Third, because the need for EOL discussions was analyzed from the perspective of home-visit nurses, it is unclear whether patients and family caregivers believe that the timing of EOL discussions is appropriate. Prior studies have shown that while many patients wanted to start EOL care before their health deteriorated, about 20% said they wanted to postpone it until near the end of life (Miyashita et al., 2020), indicating the need to consider the diversity of patient preferences regarding timing. Hence, further research is needed to determine how patients and family caregivers evaluate the results of this study and whether they agree with the nurses' decisions.

Conclusion

In this study, we explored how home-visit nurses identify the time at which patients and families need EOL discussions in Japan. Based on a qualitative content analysis of interview data from 23 home-visit nurses, we derived three themes to describe the best timing. The results suggest that home-visit nurses identify the timing of the EOL discussions as being sensitive to patients' changing health and care needs (increases in patient's total pain), changes in the family caregiver's physical or mental condition through daily care (increases in family caregiver distress), and the EOL process that patients with cancer follow (trajectory of disease). It is necessary to develop a tool or in-service educational program that will enable inexperienced or new graduate home-visit nurses to implement EOL discussions at appropriate times.

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Author Contributions

Kurumi Asaumi: conceptualization (lead), data collection (lead), data analysis (lead), writing-original draft (lead), review (lead), and

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References

- Abiodun, R. O., Daniels, F., Pimmer, C., & Chipps, J. (2019). Nurse graduates' experiences and support needs: A qualitative systematic review of South Africa's community service programme. *Curationis*, 42(1), e1–e12. <https://doi.org/10.4102/curationis.v42i1.1906>
- Akiyama, A., & Fukuyama, Y. (2020). Qualities required for new graduate visiting nurses: A qualitative study. *Journal of General and Family Medicine*, 21(3), 87–91. <https://doi.org/10.1002/jgf2.307>
- Albers, G., Francke, A. L., de Veer, A. J., Bilsen, J., & Onwuteaka-Philipsen, B. D. (2014). Attitudes of nursing staff towards involvement in medical end-of-life decisions: A national survey study. *Patient Education and Counseling*, 94(1), 4–9. <https://doi.org/10.1016/j.pec.2013.09.018>
- Colorafi, K. J., & Evans, B. (2016). Qualitative descriptive methods in health science research. *Health Environments Research and Design Journal*, 9(4), 16–25. <https://doi.org/10.1177/1937586715614171>
- Fritz, L., Dirven, L., Reijneveld, J. C., Koekkoek, J. A., Stiggelbout, A. M., Pasman, H. R., & Taphoorn, M. J. (2016). Advance care planning in glioblastoma patients. *Cancers (Basel)*, 8(11), 102. <https://doi.org/10.3390/cancers8110102>
- Fukui, S., Fujita, J., Ikezaki, S., Nakatani, E., & Tsujimura, M. (2019). Effect of a multidisciplinary end-of-life educational intervention on health and social care professionals: A cluster randomized controlled trial. *PLoS One*, 14(8), e0219589. <https://doi.org/10.1371/journal.pone.0219589>
- Grande, G. E., Todd, C. J., Barclay, S. I., & Farquhar, M. C. (1999). Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. *BMJ*, 319(7223), 1472–1475. <https://doi.org/10.1136/bmj.319.7223.1472>
- Hall, A., Rowland, C., & Grande, G. (2019). How should end-of-life advance care planning discussions be implemented according to patients and informal carers? A qualitative review of reviews. *Journal of Pain Symptom Management*, 58(2), 311–335. <https://doi.org/10.1016/j.jpainsymman.2019.04.013>

- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Joren, C. Y., de Veer, A. J. E., de Groot, K., & Francke, A. L. (2021). Home care nurses more positive about the palliative care that is provided and their own competence than hospital nurses: A nationwide survey. *BMC Palliative Care, 20*(1), 170. <https://doi.org/10.1186/s12904-021-00866-4>
- Jung, M. Y., & Matthews, A. K. (2021). A systematic review of clinical interventions facilitating end-of-life communication between patients and family caregivers. *American Journal of Hospice and Palliative Medicine, 38*(2), 180–190. <https://doi.org/10.1177/1049909120929323>
- Koyama, T., Hagiya, H., Funahashi, T., Zamami, Y., Yamagishi, M., Onoue, H., Teratani, Y., Mikami, N., Shinomiya, K., Kitamura, Y., Sendo, T., Hinotsu, S., & Kano, M. R. (2020). Trends in place of death in a super-aged society: A population-based study, 1998–2017. *Journal of Palliative Medicine, 23*(7), 950–956. <https://doi.org/10.1089/jpm.2019.0445>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.
- Lopez-Acevedo, M., Havrilesky, L. J., Broadwater, G., Kamal, A. H., Abernethy, A. P., Berchuck, A., Alvarez Secord, A., Tulskey, J. A., Valea, F., & Lee, P. S. (2013). Timing of end-of-life care discussion with performance on end-of-life quality indicators in ovarian cancer. *Gynecologic Oncology, 130*(1), 156–161. <https://doi.org/10.1016/j.ygyno.2013.04.010>
- Lynn, J. (2001). Perspectives on care at the close of life. Serving patients who may die soon and their families: The role of hospice and other services. *JAMA, 285*(7), 925–932. <https://doi.org/10.1001/jama.285.7.925>
- Mack, J. W., Cronin, A., Keating, N. L., Taback, N., Huskamp, H. A., Malin, J. L., Earle, C. C., & Weeks, J. C. (2012). Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. *Journal of Clinical Oncology, 30*(35), 4387–4395. <https://doi.org/10.1200/JCO.2012.43.6055>
- Mahmood-Yousuf, K., Munday, D., King, N., & Dale, J. (2008). Interprofessional relationships and communication in primary palliative care: Impact of the Gold Standards Framework. *British Journal of General Practice, 58*(549), 256–263. <https://doi.org/10.3399/bjgp08X279760>
- Martina, D., Geerse, O. P., Lin, C. P., Kristanti, M. S., Bramer, W. M., Mori, M., Korfage, I. J., van der Heide, A., Rietjens, J. A., & van der Rijt, C. C. (2021). Asian patients' perspectives on advance care planning: A mixed-method systematic review and conceptual framework. *Palliative Medicine, 35*(10), 1776–1792. <https://doi.org/10.1177/02692163211042530>
- Ministry of Health, Labour and Welfare. (2011). *Verification of the results of the 2010 revision of medical service fees. As shown in the special survey on cancer*. <https://www.mhlw.go.jp/english/wp/wp-hw5/dl/summary.pdf>
- Ministry of Health, Labour and Welfare. (2017). *Annual report on the aging society; 2017*. http://www8.cao.go.jp/kourei/whitepaper/w-2017/zenbun/pdf/1s2s_03.pdf
- Miyashita, J., Kohno, A., Cheng, S. Y., Hsu, S. H., Yamamoto, Y., Shimizu, S., Huang, W. S., Kashiwazaki, M., Kamihiro, N., Okawa, K., Fujisaki, M., Tsai, J. S., & Fukuhara, S. (2020). Patients' preferences and factors influencing initial advance care planning discussions' timing: A cross-cultural mixed-methods study. *Palliative Medicine, 34*(7), 906–916. <https://doi.org/10.1177/0269216320914791>
- Mori, M., Ellison, D., Ashikaga, T., McVeigh, U., Ramsay, A., & Ades, S. (2013). In-advance end-of-life discussions and the quality of inpatient end-of-life care: A pilot study in bereaved primary caregivers of advanced cancer patients. *Supportive Care in Cancer, 21*(2), 629–636. <https://doi.org/10.1007/s00520-012-1581-x>
- Mori, M., Morita, T., Igarashi, N., Shima, Y., & Miyashita, M. (2018). Communication about the impending death of patients with cancer to the family: A nationwide survey. *BMJ Supportive & Palliative Care, 8*(2), 221–228. <https://doi.org/10.1136/bmjspcare-2017-001460>
- Mori, M., Yoshida, S., Shiozaki, M., Morita, T., Baba, M., Aoyama, M., Kizawa, Y., Tsuneto, S., Shima, Y., & Miyashita, M. (2018). “What I did for my loved one is more important than whether we talked about death”: A nationwide survey of bereaved family members. *Journal of Palliative Medicine, 21*(3), 335–341. <https://doi.org/10.1089/jpm.2017.0267>
- National Institute for Health and Care Excellence. (2019). *End of life care for adults: Service delivery*. <https://www.nice.org.uk/guidance/ng142>
- Nilsson, J., Blomberg, C., Holgersson, G., Carlsson, T., Bergqvist, M., & Bergstrom, S. (2017). End-of-life care: Where do cancer patients want to die? A systematic review. *Asia-Pacific Journal of Clinical Oncology, 13*(6), 356–364. <https://doi.org/10.1111/ajco.12678>
- Portal Site of Official Statistics of Japan, e-Stat. (2020). *2020 Vital statistics of Japan, 1*. <https://www.e-stat.go.jp/>
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health, 23*(4), 334–340. [https://doi.org/10.1002/1098-240x\(200008\)23:4<334::aid-nur9>3.0.co;2-g](https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g)
- Schichtel, M., Wee, B., Perera, R., & Onakpoya, I. (2020). The effect of advance care planning on heart failure: A systematic review and meta-analysis. *Journal of General Internal Medicine, 35*(3), 874–884. <https://doi.org/10.1007/s11606-019-05482-w>
- Shepperd, S., Goncalves-Bradley, D. C., Straus, S. E., & Wee, B. (2021). Hospital at home: Home-based end-of-life care. *Cochrane Database System Review, 7*, CD009231. <https://doi.org/10.1002/14651858.CD009231.pub3>
- van Iersel, M., Latour, C. H. L., de Vos, R., Kirschner, P. A., & Scholte Op Reimer, W. J. M. (2016). Nursing students' perceptions of community care and other areas of nursing practice - A review of the literature. *International Journal of Nursing Studies, 61*, 1–19. <https://doi.org/10.1016/j.ijnurstu.2016.05.011>
- Voltz, R., Akabayashi, A., Reese, C., Ohi, G., & Sass, H. M. (1998). End-of-life decisions and advance directives in palliative care: A cross-cultural survey of patients and health-care professionals. *Journal of Pain Symptom Management, 16*(3), 153–162. [https://doi.org/10.1016/s0885-3924\(98\)00067-0](https://doi.org/10.1016/s0885-3924(98)00067-0)
- Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., Mitchell, S. L., Jackson, V. A., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA, 300*(14), 1665–1673. <https://doi.org/10.1001/jama.300.14.1665>

- World Health Organization. (2022). *International agency for research on Cancer. Global cancer observatory*. https://gco.iarc.fr/overtime/en/dataviz/trends?populations=3200&sexes=1_2&types=1&multiple_populations=1&key=total&cancers=0
- Yamaguchi, T., Maeda, I., Hatano, Y., Mori, M., Shima, Y., Tsuneto, S., Kizawa, Y., Morita, T., Yamaguchi, T., Aoyama, M., & Miyashita, M. (2017). Effects of end-of-life discussions on the mental health of bereaved family members and quality of patient death and care. *Journal of Pain Symptom Management, 54*(1), 17–26.e1. <https://doi.org/10.1016/j.jpainsymman.2017.03.008>
- Yamaguchi, T., Maeda, I., Hatano, Y., Suh, S. Y., Cheng, S. Y., Kim, S. H., Chen, P. J., Morita, T., Tsuneto, S., & Mori, M.; EASED Investigators. (2021). Communication and behavior of palliative care physicians of patients with cancer near end of life in three East Asian Countries. *Journal of Pain*

and Symptom Management, 61(2), 315–322.e1. <https://doi.org/10.1016/j.jpainsymman.2020.07.031>

- Zaros, M. C., Curtis, J. R., Silveira, M. J., & Elmore, J. G. (2013). Opportunity lost: End-of-life discussions in cancer patients who die in the hospital. *Journal of Hospital Medicine, 8*(6), 334–340. <https://doi.org/10.1002/jhm.1989>

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