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Original Article

# Visiting Nurses' Perspectives on Practices to Achieve End-of-Life Cancer Patients' Wishes for Death at Home: A Qualitative Study

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## ABSTRACT

**Objective:** This study aimed to clarify visiting nurses' perspectives on critical practices to ensure they could advocate for patients who prefer to die at home. **Methods:** Sixteen nurses, working at home-visit nursing agencies in Japan, participated in this study. Data were generated by interviews with the nurses and participant observations from nursing home-visits for six end-of-life cancer patients and were analyzed using content analysis. **Results:** Five themes emerged: (1) nursing assessment, (2) support for comfortable daily life of the patient and their family, (3) advocating for the patient's views about continuing homecare until death, (4) supporting the patient's preparedness for death, and (5) coordination with other health professionals and related facilities for a comfortable environment for the patient. In addition, the nurses sometimes used humorous responses to death-related work to change the patient's melancholy thoughts.

**Conclusion:** The present study found that the participants advocated for the patient's views about continuing homecare until death while coordinating views between the patient and their family; they further supported the patient's daily life while helping them prepare for death to achieve their wish for death at home. In addition, our study uncovered the visiting nurses' unconscious practical wisdom of using humorous responses to death-related work to alleviate the patients' feelings of hopelessness. To develop practical wisdom for using humor effectively in end-of-life care, nurses need to verbalize unconscious practices, and accumulate empirical knowledge about nursing interventions using humor, including cultural attitudes, through case study analysis.

**Key words:** Dying cancer patient, palliative home care, qualitative research, visiting nurse

## Introduction

In Japan, cancer is the primary cause of death in 28.9% of the population; the annual number of deaths exceeded

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370,000 in 2016.<sup>[1]</sup> Annual morbidity predictions for cancer also exceed 1 million cases and are growing steadily.<sup>[2]</sup> The 2017 revised basic plan to promote cancer control programs, based on the cancer control act in Japan, clearly states its goals as “building a society that can live with dignity with peace of mind.”<sup>[3]</sup>

According to a government survey, in the case of a terminal illness, 54.6% of citizens wish to pass away at home.<sup>[4]</sup> In a survey in Okinawa prefecture, 53.0% of respondents in all age groups answered that they wished to be cared for at home until death if they reach a terminal phase.<sup>[5]</sup> The traditional religious view of life, in which death at home is ideal, is still maintained in Okinawa.<sup>[6]</sup> However, the actual home death rate of cancer patients was reported to be only 13.3% in Japan and 11.8% in Okinawa, while >80% died in hospital,<sup>[7]</sup> and death at home in cancer patients was strongly affected by “access to home medical care.”<sup>[8]</sup> Behind this trend is the palliative care system situation in Japan, which is not adequately prepared to care for patients dying at home.<sup>[3]</sup> With the advent of a future super-aged society, unlike any other in history, and considering both the increase in the number of deaths from cancer and the growing need for care at home, visiting nurses have critical roles to play in supporting dying patients who wish to stay at home, even if the system is not prepared.

Previous investigations of visiting nurses who care for cancer patients have focused on nurses' thoughts regarding terminal patients' transition from hospital to home,<sup>[9,10]</sup> difficulties and barriers in-home palliative care,<sup>[11-14]</sup> care for family members who carry out the dying patient's care,<sup>[15,16]</sup> and agency- and service-related factors associated with home-based end-of-life care.<sup>[17,18]</sup> These studies suggest that it is difficult to continue home care until a patient's death if there are misunderstandings by patients and their families regarding such care,<sup>[11]</sup> caregiver shortages,<sup>[11,13,14]</sup> and lack of collaboration among homecare professionals.<sup>[9,10,12,17,18]</sup> Despite the need to facilitate and expand the roles of visiting nurses, few studies have investigated concrete practices to fulfill the wishes of terminal patients to stay at home until their deaths. The present study, therefore, aimed to examine visiting nurses' critical practices to ensure that they can advocate for patients who prefer to die at home. By clarifying these nursing practices in home palliative care, it will be possible to contribute to care strategies that facilitate patients' wishes to be cared for and die in their own homes and to provide critical suggestions regarding nursing education on this pressing topic.

## Methods

### Participants

In this study, 16 visiting nurses were chosen, using a purposive sampling strategy. Participants were working at

two home-visit nursing agencies in Okinawa, Japan, which support more than 20 home deaths of end-of-life cancer patients annually. Participants also had prior experience in supporting two patients' deaths in similar situations during the previous year.

### Statistical analysis

The data were generated through semi-structured interviews with the 16 visiting nurses and participant observations from home nursing visits for six terminal patients.

Participants were interviewed in quiet locations at their home-visit nursing agencies, as was convenient to the participants. Each interview lasted between 40 and 70 min. The main interview questions were: “How do you provide care for end-of-life cancer patients and their family members to achieve the patient's wishes for death at home?” and “on a routine basis, what do you do to pay attention to end-of-life cancer patients and their family members for continuing their home care until death?” The interviews covered the nurses' perspectives and experiences regarding their provision of support for the patients to achieve their wishes for death at home. In addition, probing follow-up questions were asked during the interviews to clarify their responses. The interviews were recorded and transcribed verbatim.

Approximately 6 h (1 h/patient) of participant observations were conducted during the nursing home-visit by using the participant-as-observer method. The participants' observations aimed to understand how nurses cared practically for terminal patients and their families, to verify conformance with interviews, and to explore nonverbalized unconscious practical wisdom from the interviews. Field notes were recorded from the participants' observations, and transcriptions of the field notes were coded for each nursing visit.

The data were analyzed using reference to Graneheim and Lundman's method of content analysis<sup>[19]</sup> as follows: First, the transcriptions of the interviews and field notes of participants' observations were read through several times to obtain a sense of the whole. Second, these texts were divided into condensed meaning units. These units were labeled with codes; the number of participants who commented on each code's contents was counted. The codes were then sorted into subcategories and categories, based on comparisons regarding their similarities and differences. Finally, themes were formulated regarding the expression of the latent content of the text.

### Trustworthiness

To establish credibility, member checking was used. The researchers ensured the depth of content and its authenticity by thoroughly identifying diverse data through several discussions and clarifications among the researchers until

a consensus was reached. After completing the analysis, a summary of the interviews and the result of the interviews' coding and categorization were returned to the participants; they confirmed that the researchers had represented their perspectives and experiences.

### **Ethical approval**

The study was approved by the ethics committee of the University of the Ryukyus, Okinawa, Japan (Approval No. 313). All the participants were informed about the study's purpose and methods. They were informed that participation in the study was voluntary and that they could refuse to participate or withdraw from the study at any time, without having any negative impact. Regarding participant observations, the patients were informed about the study's purpose and methods from a researcher and the managers of the nursing agencies. We conducted participant observations of nursing home-visits as well as asking for patient's agreement to observations.

## **Results**

### **Participant characteristics**

All participants were female and were generalist nurses who had graduated from vocational school; their ages ranged from 34 to 59 years (mean, 44.1; [standard deviation [SD]] = 7.9). Their years of nursing experience ranged from 10 to 39 years (mean, 19.7; [SD] = 7.7), and their homecare nursing experience ranged from 2 to 12 years (mean, 5.1; [SD] = 3.7).

### **Palliative nursing practices' themes**

During the data analysis, five themes emerged. Tables 1-3 present the identified themes, categories, sub-categories, and examples of typical codes. The codes emerging from the interviews and the participant observations were almost the same. Each theme is discussed briefly.

#### **Nursing assessment**

The participants evaluated the preparedness for the patients' home care based on their "assessment of the patient's and their family's understanding of their disease conditions and prognosis" and "the family member's status." They also evaluated the possibilities of continuing home care until the patient's death based on their assessment of "caregiver burden," "patient's physical status," and "the family's preparedness for continuing the patient's home care."

#### **Support for the comfortable daily life of the patient and their family**

The participants provided a sense of security to the patients and their families through "providing 24-h consultation," "providing patient symptom management," "providing an explanation to the family about the patient's

disease condition," "making opportunities for the patient and their family to be together," and "coordinating the home-visit nursing schedule according to their needs." They also created a comfortable environment for the patients' home care through "giving advice regarding nursing care and management of the patient's symptoms," "giving a sense of empowerment to the family in caring for the patient," and "providing information about available home care services and materials."

#### **Advocating for the patient's views about continuing home care until death**

The participants confirmed not only the patient's wishes but also the family's thoughts about continuing the patient's home care, and coordinated views between the patient and their family members in the case of disagreement.

#### **Supporting preparedness for the patient's death**

The participants supported preparedness for the patient's peaceful death with the patient and their family and gave ongoing emotional support to bereaved families. When patients talked about their own deaths, such as they wanted to die, or there was no meaning in life, the participants sometimes delivered humorous replies as a means of alleviating these concerns. These nursing practices were only found during the participants' observations when a researcher asked the participants to verbalize their practices. As a result, the sub-category of "care for the patient's emotional and spiritual needs using humorous replies" emerged.

#### **Coordination with other health professionals and related facilities for the patients' comfortable environments**

The participants collected further information about the patients through joint meetings with hospital staff and other homecare professionals. They also previously discussed necessary care with hospital nurses, patients, and their families; consulted with hospital nurses on the required methods for special medical treatments, such as the management of respiratory, colostomy care, and peritoneal dialysis during patient's hospitalization; and requested that the hospital keep a bed available for the patient if necessary in case of acute hospitalization and family care burden. The participants collaborated closely with the patients' home doctors for relief of pain and anxiety, relaying the prognosis prediction to patients, and supporting the patients' wishes for death at home. In addition, they collaborated with other professionals such as homecare workers, care managers, and social welfare workers to improve patient comfort.

## **Discussion**

The present study clarified five themes of visiting nurses' critical practices of providing care to an end-of-life cancer

**Table 1: Themes, categories, sub-categories, and examples of typical codes of visiting nurses' practices to continue home care for patients dying from cancer until their deaths**

Themes	Categories	Sub-categories	Examples of typical codes (Number of responding participants)
Nursing assessment	Assessment of preparedness for patient's home care	Assessing patient and their family's understanding, and perception of patient's disease conditions and prognosis	I ask the patient and their family how they accept the patient's disease and perceive their understanding regarding the patient's condition. (5) I ask the patient's family how they feel about the patient's condition specifically, compared to a week ago, and I confirm their understanding of the patient's disease condition. (2) When the home-care nursing starts, I ask the patient and their family how they are informed by a doctor about patient's disease and the prognosis. (1)
		Assessing patient's family status	When the home-care nursing begins, I identify information regarding family members, the main provider of home care, and family support. (4) At the start of home care, I ask the family's thoughts regarding home care separately from patient. (1)
	Assessment of possibilities for continuing home care until patient's death	Assessing physical and psychological burden of caregivers	<u>I identify caregiver's condition consciously.</u> (4) When the patient's condition grows worse, I confirm the family's willingness to continue home care for the patient. (3) <u>I ask the patient's family about whether they have any difficulties in the patient's home care.</u> (2) In the case of an elderly caregiver, if the caregiver experiences care burdens, I discuss whether to provide respite care or home-care services. (2) If the caregiver experiences care burdens, I discuss with the caregiver whether to provide respite care services to the patient. (2)
		Assessing patient's physical status	<u>I evaluate the patient's condition, whether pain and other symptoms are relieved and they live comfortably.</u> (6) I assess the patient's physical condition from their laboratory data. (3) I predict the patient's course of symptoms and prognosis from patient's clinical condition. (2) When the patient is close to death, I anticipate sudden changes in the patient's symptoms and condition. (2)
		Assessing patient and their family's preparedness for continuing patient's home care	I ask the patient's family whether they can continue to care for the patient at home. (5) I evaluate whether the family can continue to care for the patient at home until patient's death with the support of home nursing staff. (2) I assess the possibilities of continuing home care through the family's competence as a caregiver and cooperation among family members for supporting the caregiver. (1)
Support for comfortable daily life of the patient and their family	Provision of a sense of security to patient and their family	Providing 24-hour consultation	<u>I contract to provide 24-hour consultation for giving a sense of security when the patient and caregiver are in need, and to relieve the patient's pain, including emotional pain and anxiety.</u> (6) If the patient has strong anxiety, I often call patient to ask whether they are having problems. (2)
		Providing patient's symptom management	If the patient has any complaints, such as pain, dyspnea, delirium and fever, I visit early to respond to their symptoms. (3) <u>I advise patient how to take drugs (e.g. analgesics and laxatives) according to the patient's symptom level.</u> (3) If the patient's pain control is bad, I change the dose and type of drug under doctor's orders, and I reevaluate their pain management. (2)

Underlined codes emerged from both the interviews and the participants' observations. Non-underlined codes emerged from the interviews only

patient who prefers to die at home, in order to ensure they can advocate for the patient as follows: (1) nursing assessment, (2) support for the comfortable daily life of the patient and their family, (3) advocating for the patient's views about continuing home care until death, (4) supporting the patient's preparedness for death, and (5) coordination with other health professionals and related facilities for a comfortable environment for the patient. In addition, a characteristic practice in this study was that the participants sometimes used humor in their established rapport with patients as a response to death-related work to alleviate the patients' feelings of hopelessness.

The participants confirmed their understanding of the patient's condition and prognosis and also inquired about the patient's advance directives. Silveira *et al.*<sup>[20]</sup> found that patients who had prepared advance directives received

care that was strongly associated with their preferences. This indicates that advance care planning practiced by nurses for terminal cancer patients may contribute to the patients achieving their goal of passing away at home.<sup>[21]</sup> To achieve this and to honor patients' wishes, it is important for visiting nurses to continue to offer predictive prognosis to patients and their families and to repeatedly confirm a patient's willingness to stay at home until death. In addition, in terms of the patient's family, bereaved family members who cared for dying patients at home in accordance with the patient's wishes reported positive outcomes (e.g., feelings of accomplishment, improved family relationships)<sup>[22]</sup> and felt personal growth through their caring experiences.<sup>[23]</sup> This suggests that supporting a patient's wishes leads to positive outcomes overall for the patient's family.

**Table 2: Themes, categories, sub-categories, and examples of typical codes of visiting nurses' practices to continue home care for patients dying from cancer until their deaths (continued)**

Themes	Categories	Sub-categories	Examples of typical codes (Number of responding participants)	
Support for comfortable daily life of the patient and their family	Provision of a sense of security to patient and the family	Providing an explanation to the family about patient's disease condition	I tell the patient's family about changes in the patient's symptoms, prognosis prediction, and possibility of sudden changes. (13) I explain to the patient's family about the patient's disease condition, depending on the depth of their understanding. (2)	
		Making opportunities for patient and the family to be together	I provide the patient's family with physical contact with the patient through aromatherapy massage. (2) When the patient has depressed consciousness, I ask the patient's family to stay by their bedside and touch him/her. (2)	
		Coordinating of home-visit nursing schedule according to the patient and their family's needs (frequency, time)	I coordinate home visit frequency according to the patient's needs (e.g., their anxiety and economic situation). (6) I make it a rule to visit the patient more frequently if they have high medical needs. (2) In the early days after discharge from hospital, I make it a rule to visit the patient more frequently. (1) I set up home visiting times in consideration of the patient and their family's daily life patterns. (1)	
	Creation of a comfortable environment for patient's home care	Giving advice regarding nursing care (including simple methods of medical treatment) and how to manage patient's symptoms	If the patient needs suctioning, I give the patient's family advice on how to administer suction in an easy and repeatable manner. (6) I give the patient's family advice on how to give nursing care in easily understandable way. (3) <u>If the patient has no appetite and poor dietary intake, I give their family advice on how to cook, plan menus, and foodstuff.</u> (2) <u>I advise the family about the patient's room environment (e.g., temperature, air condition, illumination) and how to regulate the patient's life (taking a walk and light exercise in the daytime).</u> (2)	
		Giving a sense of empowerment to the family to care for patient	I discuss whether the patient's family are prepared to deal with the patient's home care, and encourage their confidence in home care. (5) I tell the family caregiver that I admire them for their efforts in the patient's home care. (1)	
		Providing information about available home care services and materials.	I recommend the use of beds, air mattress and nursing care materials according to their needs. (2) I provide information about available home care services to the patient and their family to continue home care comfortably. (1)	
	Advocating for the patient's views about continuing home care	Confirmation of patient's true feelings for home care	Confirming patient's willingness to stay at home until death	I ask about the patient's thoughts about continuing home care often, because the patient's emotions change with each day. (4) When the patient says that they will be admitted to the hospital, I discern his/her real intention for home care. (2)
			Identifying patient's requests for home care nurses	I confirm the patient's desire to do what the patient wants to do. (1) <u>I ask whether the patient's hopes for the home nurse to do something.</u> (1)
		Coordinating views on home care between patient and their family	Coordinating views on continuing home care until patient's death between patient and their family Coordinating views on advance directive of patient in case of sudden change between patient and their family	If there is disagreement between the patient and their family about continuing home care, I provide face-to-face meetings between the patient and family. (4) If the patient/their family can't express their own thought directly with each other, I tell them about each their thoughts. (1) At the start of home care, I ask the patient whether he/she wants to receive treatment (e.g., oxygen inhalation, drip infusion, sedation) in case of sudden change. (2) I coordinate views on the patient's advance directive between the patient and their family through the patient's family conference in the case of disagreement. (2)
Supporting preparedness for the patient's death	Support for patient's peaceful death at home	Supporting patient's family to prepare them mentally for the patient's death	I explain to the patient's family about the dying process (e.g., signs, changes in symptoms) and support the patient's family to prepare psychologically for the patient's death. (6) I contract to support the patient's family until the end, and encourage the family's decision, which is the patient wants to stay at home until their death as per their wishes. (2)	
		Giving advice to patient's family on how to care for patient during the dying process	I advise the patient's family that they talk softly to patient until the end, because they can hear the family's voices. (1) I advise the patient's family that they stay with the patient, holding a patient's hand until the end. (1) Even if the patient's breathing stops, I ask the patient's family not to call an ambulance and to contact us as soon as possible. (1)	
	Alleviating grief for patient's death	Caring for patient's emotional and spiritual needs using humorous replies Caring for bereaved family	<b>When the patient talks about their death, I sometimes tell the patient to change a gloomy thought, saying, "You can't pass away now, it's a place where we can't go without a guide to the patients."</b> (3) I tell the patient, "I think it's not your time to die, because your wife has not yet come to pick you up from heaven." (1) If I care very deeply for the bereaved family's mental health, I visit at the proper time and listen to their thoughts. (2) At the end of the first anniversary of the patient's death, we sometimes send the bereaved family a letter or greeting card. (1)	

Underlined codes emerged from both the interviews and the participants' observations. Non-underlined codes emerged from the interviews only. Bold codes and bold sub-category emerged from the participant observations only

Conversely, in a survey in Okinawa, respondents who did not want to die at home in the case of reaching a terminal phase responded that way primarily because they did not

want to make trouble for their families.<sup>[8]</sup> In Japan, there was a high prevalence of entrusting end-of-life decisions to the family as opposed to the individual, when compared

**Table 3: Themes, categories, sub-categories, and examples of typical codes of visiting nurses' practices to continue home care for patients dying from cancer until their deaths (continued)**

Themes	Categories	Sub-categories	Examples of typical codes (Number of responding participants)
Coordination with other health professionals and related facilities for comfortable environments for the patient	Coordination with patient's hospital staff	Collecting patient information through participating in joint meetings consisting of hospital staff and home care professionals	When patient discharges from hospital, I collect the patient's information through participating in joint meetings, consisting of hospital staff and other homecare staff. (2) I ask the patient's hospital staff about necessary supplies for the patient's home care. (2)
		Preparing care and medical treatment for patient's home care during hospitalization	I coordinate with family members for them to learn care skills of sputum suction from hospital nurses. (2) If patient needs special medical treatments (e.g., colostomy, or management of respiratory, parenteral nutrition, and peritoneal dialysis), I confirm care plans during patient's hospitalization. (4)
		Coordinating hospitalization to care for patient's acute treatment and alleviating family care burden as necessary	I request the hospital keep a bed available for the patient as necessary, in case of acute hospitalization and family care burden. (2)
	Cooperation among home care professionals	Sharing information about patient's status at home with patient's hospital staff	I provide the patient's information about home care to the patient's hospital nursing staff. (2) When the patient dies, I share the patient's information about how they died with the patient's hospital staff. (1)
		Sharing information about patient and the family among home-visit nurses who care for patient	When the patient is close to death, we share information about the patient's condition, prognosis prediction, and the family's state. (2) At the start of home care, I provide the patient's information about their condition and the family's status to other nurses. (2)
		Collaborating with patient's home doctor to improve patient comfort	If the patient's family doesn't understand the patient's condition, I ask the doctor to explain the patient's condition to them. (2) I tell the doctor what has been on the minds of the patient and their family, if they can't speak freely to the doctor. (2)
Collaborating with homecare staff to care for patient	I prepare the patient's homecare environment with cooperation from homecare staff (e.g., homecare workers, care managers, social welfare workers). (6) In case of a patient who lives alone, I prepare the patient's homecare environment with a public health nurse, volunteers, and neighbors and friends. (1)		

All codes emerged from the interviews only

with Western countries.<sup>[24]</sup> The general population in Japan might tend to emphasize relationships with others rather than autonomy.<sup>[24]</sup> These results suggest that patients might not reveal their true willingness to stay at home, out of consideration for their families. Because of these concerns, visiting nurses need to uncover patients' true thoughts, elicit an emotion, then reconcile opposing points of views regarding home care between patients and their families.

Each of the participants had discussions about necessary care with patients, their families, and hospital staff, to prepare for home care and give a sense of security while the patient was still hospitalized. During the patients' home care, the participants provided 24-h care support for them so that they could live with security. In a survey of people who provided care at home for family members with terminal cancer, caregivers often expressed a high rate of difficulty related to the "patient's pain and condition," with approximately 60%–80% of them having concerns about "care burden."<sup>[25]</sup> Because of these concerns, the coordination of necessary medical care, including pain control and other relief, is emphasized.<sup>[12]</sup> This sense of security is a significant component of well-being for patients and their families and underpins heightened confidence about their ongoing daily lives.<sup>[26]</sup> Poor discharge planning, poor coordination

of necessary medical care, including pain control and other relief,<sup>[12]</sup> and family care burden<sup>[13]</sup> were barriers to dying at home and promoters of hospital admission. Taking these precautions will provide patients and their families with a sense of security and trust; therefore, visiting nurses are required to prioritize this collaboration between hospital staff and homecare professions, coordinating treatment planning before home care begins. In addition, this indicates that better comprehension of caregivers' experiences can help professional nursing staff to understand what will promote caregiver confidence.<sup>[27]</sup> Thus, nurses need to understand the experiences of caregivers fully and give proper attention to their physical and mental condition.

The participants also supported the patient's family as they spent quality time with the patient while recommending patient massage to provide the family with physical contact. Opportunities for the family to participate in care using massage improved relationships between the patient and their family, and helped to prepare the family to deal with the patient's death.<sup>[28]</sup> This suggests that nursing practices that create opportunities for offering close physical contact between the patient and their family also promoted spiritual well-being.

The present study uncovered the visiting nurses' nonverbalized and unconscious practical wisdom of using

humorous responses to death-related work with patients through the participant observations. Light-hearted talk of death has been shown to have a psychological effect of detaching the terminally ill from their own deaths.<sup>[29]</sup> Using humor in palliative care reduced emotional tension and stress, fostered relationships between patients and healthcare workers,<sup>[30,31]</sup> had efficacy for pain relief and improved coping skills and quality of life.<sup>[29-32]</sup> These outcomes were obtained from studies in the Western-European cultural setting, and we found no study on nursing interventions using humor in Japanese palliative care. However, it appeared that our study's participants subconsciously created an emotional atmosphere that allowed the expression of grief by delivering humorous replies to the patients' gloomy thoughts about their deaths. To develop practical wisdom and build a solid empirical foundation for using humor effectively in end-of-life care, nurses need to verbalize unconscious practices and accumulate empirical knowledge about nursing interventions using humor, including cultural attitudes, through case study analysis.

As mentioned, we clarified the critical practices of visiting nurses to ensure that they could advocate for patients who preferred to die at home. When it comes to the concept of a "good death," most Japanese people have emphasized physical and psychological comfort, environmental comfort and dying in a favorite place, a good relationship with family and medical staff, maintaining hope and pleasure, not being a burden to others, and being respected as an individual.<sup>[33]</sup> The nursing practices identified from the present study met these requirements of a good death. At the same time, we uncovered the core clinical competencies required for this care. These findings will help expand our understanding of how visiting nurses might actively engage in constructing homecare systems to assess and support terminal patients and their families appropriately so that they might achieve the patient's peaceful death at home. Toward the advent of the future super-aged society, we need to cultivate nurses who are not only capable of these comprehensive practices but who also have the skills to use humor appropriately in palliative care based on a solid empirical foundation, to contribute to the quality of life of end-of-life patients and their families.

### Limitations

This study is limited through being based on two home-visit nursing agencies in Okinawa, Japan, so the results may not support broader generalization. Therefore, it is unlikely to reflect the state of other countries with different healthcare systems. However, our detailing of common nursing practices for terminal patients undergoing home care may help provide appropriate strategies across cultures.

## Conclusion

The present study found that the participants advocated for the patients' views about continuing home care until death while coordinating views between the patients and their families; they further supported the patients' daily lives while helping their preparedness for death to achieve their wishes for death at home. These findings contribute to the care strategies for supporting end-of-life cancer patients and their families' wishes to empower them to face death in the comfort of their own home. In addition, our study uncovered the visiting nurses' unconscious practical wisdom of using humorous responses to death-related work with patients to alleviate the patients' feelings of hopelessness. To develop practical wisdom and build a solid empirical foundation for effectively using humor in end-of-life care, nurses need to verbalize unconscious practices so that the scientific community can accumulate their experiences and scientific knowledge about nursing interventions using humor.

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### Conflicts of interest

There are no conflicts of interest.

## References

1. Director-General for Statistics and Information Policy. Ministry of Health, Labor and Welfare. Vital Statistics in Japan: Trend up to 2016. Tokyo: Ministry of Health Labor Welfare. Available from: <https://www.mhlw.go.jp/toukei/list/dl/81-1a2.pdf>. [Last accessed on 2018 Nov 29].
2. Katanoda K, Kamo K, Saika K, Matsuda T, Shibata A, Matsuda A, *et al.* Short-term projection of cancer incidence in Japan using an age-period interaction model with spline smoothing. *Jpn J Clin Oncol* 2014;44:36-41.
3. Ministry of Health, Labor and Welfare. The 2017 Revised Basic Plan to promote cancer control programs in Japan Ministry of Health, Labor and Welfare. Available from: <https://www.mhlw.go.jp/file/06-Seisakujouhou-10900000-Kenkoukyoku/0000196975.pdf>. [Last accessed on 2018 Nov 29].
4. Annual Report on the Aging Society; 2017. Available from: [http://www8.cao.go.jp/kourei/whitepaper/w-2017/zenbun/pdf/1s2s\\_03.pdf](http://www8.cao.go.jp/kourei/whitepaper/w-2017/zenbun/pdf/1s2s_03.pdf). [Last accessed on 2018 Nov 29].
5. Okinawa Prefecture. Kenminshikichosa. Available from: [http://www.pref.okinawa.jp/imu\\_kokuho/iryotaisaku/kennminshikityousa/kekkanogaiyou.pdf](http://www.pref.okinawa.jp/imu_kokuho/iryotaisaku/kennminshikityousa/kekkanogaiyou.pdf). [Last accessed on 2019 Mar 18].
6. Kondo N. Traditional religion and terminal care in the Ryukyus, Southern Japan. *Nihon Kosho Eisei Zasshi* 1992;39:799-808.
7. Okinawa Prefecture. The 2017 Revised Basic Plan to Promote

- Cancer Control Programs in Okinawa Prefecture. Available from: <https://www.pref.okinawa.jp/sote/hoken/kenkotoyoju/cancer/gantaisakusuishinkeikaku.html>. [Last accessed on 2019 Mar 18].
8. Igarashi M, Satou K, Shimizu M, Kanno Y, Kanno K, Kawahara R, *et al.* Factors affecting death at home. *Palliat Care Res* 2014;9:114-21.
  9. Kasai Y. Cognition and decision making of home care nurse regarding the transition from hospital to home or terminal cancer patients. *J Jpn Soc Cancer Nurs* 2006;20:39-50.
  10. Danielsen BV, Sand AM, Rosland JH, Førland O. Experiences and challenges of home care nurses and general practitioners in home-based palliative care – A qualitative study. *BMC Palliat Care* 2018;17:95.
  11. Osono Y, Ishi Y, Miyashita M. Obstacles to continued home care for terminal cancer patients from perspective of visiting nurse. *J Jpn Soc Cancer Nurs* 2015;29:44-53.
  12. O'Brien M, Jack B. Barriers to dying at home: The impact of poor co-ordination of community service provision for patients with cancer. *Health Soc Care Community* 2010;18:337-45.
  13. Jack B, O'Brien M. Dying at home: Community nurses' views on the impact of informal carers on cancer patients' place of death. *Eur J Cancer Care (Engl)* 2010;19:636-42.
  14. Osono Y, Ishi Y, Miyashita M. Issues and solutions with the care of end-of-life cancer patients at home from the perspective of visiting nurses. *J Jpn Soc Cancer Nurs* 2012;26:52-60.
  15. Saiki C, Itoh E, Tadaka E, Arimoto A, Okochi A, Shiratani K, *et al.* Experience and support of family caregivers of terminal cancer patients in approaching death at home from the view point of home visiting nurses. *J Jpn Acad Community Health Nurs* 2015;18:56-64.
  16. Furuse M. Visiting nurses' support for the mental uncertainty experienced by families of terminal cancer patients during care. *Jpn J Res Fam Nurs* 2014;19:90-100.
  17. Igarashi A, Kurinobu T, Ko A, Okamoto Y, Matsuura S, Feng M, *et al.* Factors related to the provision of home-based end-of-life care among home-care nursing, home help, and care management agencies in Japan. *BMC Res Notes* 2015;8:434.
  18. Nakanishi M, Niimura J, Nishida A. Factors associated with end-of-life by home-visit nursing-care providers in Japan. *Geriatr Gerontol Int* 2017;17:991-8.
  19. Downe-Wamboldt B. Content analysis: Method, applications, and issues. *Health Care Women Int* 1992;13:313-21.
  20. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010;362:1211-8.
  21. Ishikawa T, Fukui S, Okamoto Y. Advance care planning and home death in patients with advanced cancer: A structured interview analysis. *Int J Palliat Nurs* 2018;24:418-26.
  22. Koop PM, Strang VR. The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clin Nurs Res* 2003;12:127-44.
  23. Wong WK, Ussher J, Perz J. Strength through adversity: Bereaved cancer carers' accounts of rewards and personal growth from caring. *Palliat Support Care* 2009;7:187-96.
  24. Voltz R, Akabayashi A, Reese C, Ohi G, Sass HM. End-of-life decisions and advance directives in palliative care: A cross-cultural survey of patients and health-care professionals. *J Pain Symptom Manage* 1998;16:153-62.
  25. Ishii Y, Miyashita M, Sato K, Ozawa T. A family's difficulties in caring for a cancer patient at the end of life at home in Japan. *J Pain Symptom Manage* 2012;44:552-62.
  26. McKenzie H, Boughton M, Hayes L, Forsyth S, Davies M, Underwood E, *et al.* A sense of security for cancer patients at home: The role of community nurses. *Health Soc Care Community* 2007;15:352-9.
  27. Soroka JT, Froggatt K, Morris S. Family caregivers' confidence caring for relatives in hospice care at home: An exploratory qualitative study. *Am J Hosp Palliat Care* 2018;35:1540-6.
  28. Minami Y, Hayama Y, Oishi F. The effectiveness of nursing intervention in providing an opportunity for family members to participate in the care of terminal cancer patients – The use of aroma massage. *J Chiba Acad Nurs Sci* 2014;20:39-46.
  29. Langley-Evans A, Payne S. Light-hearted death talk in a palliative day care context. *J Adv Nurs* 1997;26:1091-7.
  30. Dean RA, Gregory DM. More than trivial: Strategies for using humor in palliative care. *Cancer Nurs* 2005;28:292-300.
  31. Claxton-Oldfield S, Bhatt A. Is there a place for humor in hospice palliative care? Volunteers say "Yes"! *Am J Hosp Palliat Care* 2017;34:417-22.
  32. Ridley J, Dance D, Pare D. The acceptability of humor between palliative care patients and health care providers. *J Palliat Med* 2014;17:472-4.
  33. Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y. Good death in cancer care: A nationwide quantitative study. *Ann Oncol* 2007;18:1090-7.