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## A Model of Spiritual Care of Home Visiting Nurses for Patients with Terminal Cancer Using Qualitative Study

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**Abstract** This study aimed to explore the spiritual care process of home visiting nurses for patients in terminal phase of advanced cancer. Semi-structured interviews were conducted with eight registered nurses who had experience as a home visiting nurse for over three years in end-of-life care. Data were analyzed by modified grounded theory approach. As a consequence of analysis, the following two core categories were extracted; 1) end-of-life total care with two sub categories: basic care with limited resources and support for family carers, and 2) achieving spiritual care with two sub categories: clinical reasoning to clarify spiritual pain and intervention and evaluation of spiritual care. This study revealed that home visiting nurses have achieved spiritual care based on end-of-life total care, and the process of providing spiritual care was; basic care with limited resources, support for family carers, clarifying spiritual pain through clinical reasoning and intervention and evaluation of spiritual care. The process of achieving spiritual care was closely related to the nursing process which consists of assessment and diagnosis, planning, intervention, evaluation. Home visiting nurses need opportunities for learning about clinical reasoning concerning spiritual pain to achieve end of life spiritual care.

*Key words:* spiritual care, home visiting nurses, terminal cancer, modified grounded theory approach, Japan

### Introduction

Cancer has been the major cause of death in Japanese population since 1981 with one third of people dying from cancer from 2005. The Basic Law for Anticancer Act was enacted in Japan in 2006 and promotion of home healthcare was commenced. More than half of Japanese older adults (more than 60 years old) wish to spend the terminal phase of their illness at home but the actual rate of home death is about 13% of the population.<sup>1</sup> In case of cancer, it is about 8%.<sup>2</sup> To fulfill the patient's wish of going home and dying at

home, home visiting nurses need to relieve patient's pain with advanced care, ease the burden on family caregivers, manage daily life including individual needs and requests, provide emotional support to the dying and their family members, and also allow patients to discuss their spiritual issues. If the spiritual needs are not met, the QOL in people at their final phase of life will be decreased and they will finish their life remaining with their concerns and unfinished business. Therefore, it is important for visiting nurses to realize the spiritual pain of patients, determine its causes and triggers, select an appropriate

intervention to improve spiritual care.

Health professionals are required to conduct spiritual assessment and intervention among patients with cancer in order to enhance their quality of life (QOL). In Japan, there are 386 specialist hospitals that can provide advanced palliative care including spiritual care.<sup>3</sup> There are many patients at the end of life who do not have enough mental and physical strength to prepare for the own death and caregivers also hesitate to give advice to patients. Home visiting nurses are required to provide end of life care solely within a limited time frame<sup>4</sup> under completely different settings from a hospital to deal with their spiritual pain and concerns. These concerns can include regrets and worries which can remain unresolved by the patient and others until the patient's end.<sup>5</sup>

There is no standardized definition for spiritual pain, and it remains controversial whether spiritual pain is same as suffering and spiritual distress, and it is the polar opposite of spiritual well-being.<sup>6</sup> Murata defined spiritual pain clearly as "pain caused by extinction of the being and the meaning of the self," and also defined spiritual care as "the care to treat spiritual pain."<sup>7,8</sup> In this study we use Murata's definition.

There is no previous research about spiritual care by home visiting nurses at home, although there are studies<sup>9-11</sup> relating to hospital-based home care or home hospice care or palliative care by certified nurses, who were dispatched from hospital. Usually these hospitals have a palliative care unit and experienced teams. Providing appropriate spiritual care is needed but Japanese home visiting nurses do not have enough time to conduct the care and there are no studies revealing detailed spiritual care processes.

Home visiting nurses, who interact with patients at their terminal stage of illness, need to recognize the importance of spiritual care. Clarifying the process of spiritual care of successful home visiting nurses will help other nurses and health professionals to use the process. This process is not achieved by only one visit but achieved by visiting many times and building relationships with people at home.

This study aimed to explore the spiritual

care process of home visiting nurses for patients in terminal phase of advanced cancer.

## Methods

### Design

This study used the modified grounded theory approach (M-GTA).<sup>12-15</sup> This approach was developed by adopting the theoretical and content properties of the grounded theory approach (GTA).<sup>16</sup> and then adding some modifications. M-GTA is a qualitative research methodology, for extracting concepts that are helpful to explain the process of human thoughts and behavior. M-GTA was judged to be suitable for this study because its aim was to develop a theory of a spiritual care process. The differences between GTA and M-GTA are that GTA segments data to avoid being influenced by participants' perspective and analyze objectively, while M-GTA acknowledges participants' perspective and analyze data by integrating objectivism and social constructionism.

M-GTA values the context of the data and interpretation so that the data were not treated as separate words or sentences and elements.

### Participants

The nursing directors of four home nursing stations were contacted by the researchers in a city of the Chugoku district of Japan, which has a population approximately 170,000. These home nursing stations have many cases of end-of-life care for patients with terminal illnesses including cancer although they are not attached to a palliative care unit. The selection criteria for the study included nurses who worked at an independent facility from the hospital and provided end-of-life care to patients; had more than three years' experience in end-of-life care but were not certified nurse specialists in cancer nursing or in palliative care. Eight registered home visiting nurses agreed to being interviewed after the nursing directors' approval at each home nursing station.

### Data collections

Semi-structured interviews were conducted for approximately 45 minutes in a private

room using an interview guide which was created through discussions between researchers. The main interview questions were as follows: 1. Have you ever noticed any concerns or unfinished business of patients in the terminal phase? 2. What are your priorities that you value in delivery of end-of-life care? 3. How do you assess and intervene with patient's spiritual needs? Data were collected from August to September 2016, and interviews were recorded with participants' consent and later transcribed verbatim.

### Data analysis

M-GTA requires analysis theme and target. First, this was set as "Method of assessment and intervention for spiritual care by home visiting nurses." Second, we read the data focusing on the context thoroughly, interpreted the meaning, and noticed the data which were based on the theme and focused person. Extracted concepts were then taken from the data and described with a name and definition of each concept. This process is different from segmentation used in GTA, we described the reason we chose the data and how we interpreted the content of the examples in the data variation, and recorded information in the theoretical notes. This stage used an analysis worksheet which consisted of concept name, concept definition, data variations, and theoretical notes. We examined the relationships among the extracted concepts, and generated categories of similar concepts. Third, the relationships and comparison among those categories including concepts that were examined repeatedly, the core categories were found through this process. That

is, sub categories were generated by analyzing extracted concepts based on the relations and similarities and core categories were generated by abstracting sub categories based on their relations and similarities. Fourth, we created a diagram and a story line, to explain the spiritual care process with categories and concepts under the diagram. Finally, we developed a theory of the spiritual care process.

In this process of analysis, discussion was held until all researchers reached agreement from the formulation to analysis. The analysis procedure guide was planned, with analysis theme, extract concept, generate category, and theory creation. All transcribed verbatim data and result of analysis were shared, checked and analyzed by an experienced interdisciplinary research team, and the trustworthiness of this research process was confirmed.

### Ethical considerations

The participants were informed about this study and assured that study participation was voluntary. They were also informed that they could refuse participation at any time even after data collection. This study was approved by the Ethical Review Board of School of Health Sciences Yamaguchi University Graduate School of Medicine in Japan (No. 386).

### Results

#### Participants' characteristics

A total of eight home visiting nurses were interviewed. All nurses were female and demographics are summarized in Table 1.

Table 1 Profiles of participants

Participants; position	Sex	Age	Yrs. Experience as a nurse	Yrs. experience as a home visiting nurse	Number of end-of-life care cases at home
A; director	Female	50's	20	8	80
B; chief	Female	40's	27	10	20
C; director	Female	40's	27	19	50
D; staff	Female	50's	25	6	20
E; director	Female	50's	31	6.5	15
F; staff	Female	30's	15	4	9
G; staff	Female	40's	28	4	8
H; staff	Female	30's	11	4	5

### Categories and concepts

The qualitative data were analyzed using M-GTA, concepts and categories as shown in Table 2, and created spiritual care model

with illustration (Fig. 1) by the relationships between categories. As a consequence of analysis, two core categories and four sub categories were extracted. The core categories were:

Table 2 Categories and concepts

Core category	Sub category	Concept	Definition of concept
End-of-life total care	Basic care with limited resources	Being respectful	Being polite, asking permission, extracting information
		Providing Patient-centered care	Providing care which prioritized patient's demands rather than their families or health professionals
		Alleviating pain	Providing care prioritizing physical pain relief
		Remaining at home	Accomplish patients' wishes such as undertaking activities not able to be done in hospital
	Support for family carers	Encouraging family to face the distress	Intervening and encouraging family caregivers' involvement to face the distress for unacceptable death of their beloved person
		Helping daily lives	Involvement in patients' conventional daily lives with their families at home
Achieving spiritual care	Clinical reasoning to clarify spiritual pain	Determining level of readiness	Knowing patients' level of readiness to accept their death and their predicted path to death
		Accepting patients as they are	Accepting patient's worries, upset, anger, rejection by the nurse
		Establishing therapeutic relationship with patients	Therapeutic relationship to encourage patients to realize their true wish and wants at their final phase of life
		Searching for appropriate intervention,	Questioning and searching repeatedly for patients' wishes, addressing distress and concern
		Allowing patients to grieve	Giving patient space to grieve
		Preparing for timely intervention	Considering and being prepared to intervene at the right time with spiritual care
	Intervention and evaluation of spiritual care	Integrating care	Providing spiritual care, psychosocial care, physical care for patient's spiritual pain as a key person of the team
		Team debriefing	Conducting case conference after the patient's death with health professionals for review of end-of-life care process

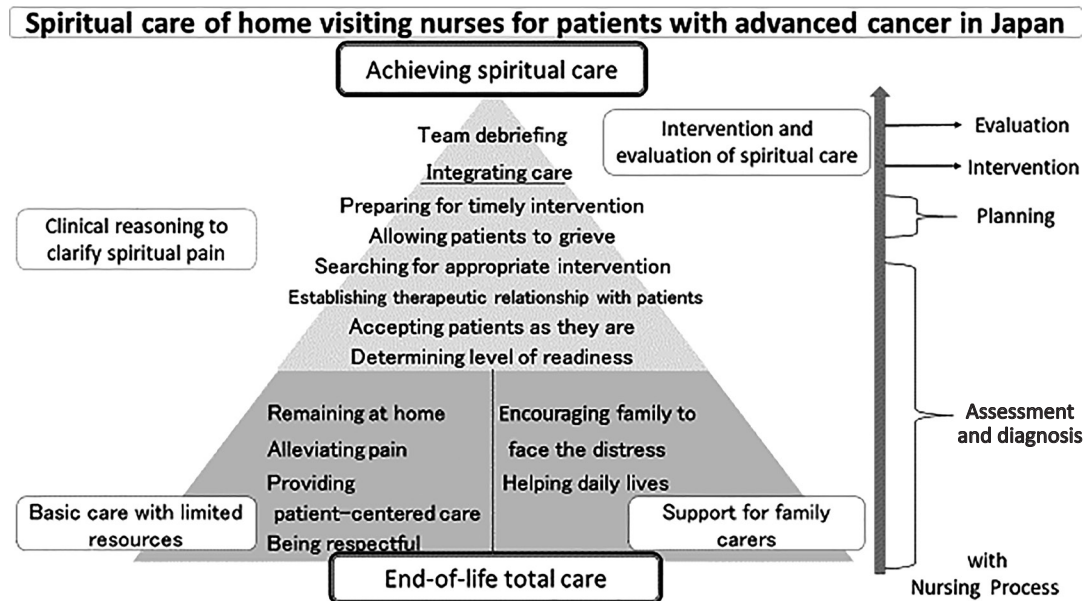


Fig. 1 Spiritual care model

<sup>i)</sup> end-of-life total care, <sup>ii)</sup> achieving spiritual care. <sup>iii)</sup> End-of-life total care consisted of 2 sub categories: <sup>a)</sup> basic care with limited resources, <sup>b)</sup> support for family carers. <sup>iii)</sup> Achieving spiritual care consisted of two sub categories: <sup>a)</sup> clinical reasoning to clarify spiritual pain and <sup>b)</sup> intervention and evaluation of spiritual care. The story lines of this study was that home visiting nurses' have achieved spiritual care based on end-of-life total care and the care process was created by basic care with limited resources, support for family carers, clinical reasoning to clarify spiritual pain and intervention and evaluation of spiritual care.

*Core category: End-of-life total care*

End-of-life total care consisted of two sub categories: <sup>a)</sup> basic care with limited resources and it consisted of four concepts of care: being respectful, providing patient-centered care, alleviating pain, and remaining at home. The other category is <sup>b)</sup> support for family carers and it consisted of two concepts of care: encouraging family to face the distress and helping daily lives.

*Sub category: Basic care with limited resources*

Being respectful:

Home visiting nurses described taking care of patients respectfully, and creating a

comfortable environment to talk about themselves. One participant said:

*I provide respectful care by using polite language, treating patients carefully and slowly, getting permission to give care or to talk to them (as some patients feel tired of speaking), at their terminal phase.(PF)*

Providing patient-centered care:

Home health care is impossible without family caregivers and respect for family member's sentiment is essential, but at the terminal phase, respect in the patient's sentiment is the most important and sometimes it is prioritized over medical care in order to improve the patient's QOL. One experienced participant stated:

*Of course we need to give consideration to family members, but what the patient wants to do comes first in the care. Sometimes I ask doctor to adjust medication.(PA)*

Alleviating pain:

When the patient has pain, the home visiting nurses give first priority in alleviating the pain to pursue their comfort. A number of participants expressed this as follows:

*I focus on painless and comfortable care to patients.(PH)*

Remaining at home:

Patients who receive home care instead of being admitted to a hospital can complete unfinished business, so home visiting nurses do

their best to enable the patients' wishes to be fulfilled. One participant explained:

*You would never be discharged if you have a fever of 39 degrees Celsius, but when the patient was at home with that fever, and even though she had ascitic fluid, she used to go to pick up her child at a nursery school. To realize her desire to go to an athletic meeting for her child, home visiting nurses tried what they could do such as bring her fever down and relieve pain, and at the end she was able to join the meeting which she almost had given up going.(PC)*

Sub category: Support for family carers  
Encouraging family to face the distress:

In order to realize the end of life at home, it is indispensable for home visiting nurses to take care of family members who look after the terminal phase of patients. Family carers have various feelings and wishes, and as in the case below, a husband who was taking care of his wife did not want to listen to her medical condition and did not try to talk about the future plan for her care. It is an important role of home visiting nurses to palliate the family's suffering. One participant recounted:

*One caregiver could not accept the patient's condition of a terminal cancer, "I don't want to hear about her illness. If I hear about it she will get worse, so I am OK not knowing as I am now." To help the caregiver to start facing the distress of his wife's death, the home visiting nurse tried to encourage the caregiver to realize the importance of his involvement for his spouse: "We cannot stay as it is. You are the one who can support your wife."(PC)*

Helping daily lives:

Home visiting nurses assist home medical care because they considered that, as it was important for patients to stay at home at the end of life, then the patient and family can live their life as usual, even after the patient died. An experienced participant stressed:

*I advised family members, "You can just stay the same as always." So they did the normal life, children went to school, and when the patient was dying, the child said "I am hungry!" After the patient's death, the family members took a bath with the*

*dead patient as the patient liked the bath which was designed by the patient, the daughter played the piano..."(PC)*

Core category: Achieving spiritual care

Achieving spiritual care consisted of two sub categories, <sup>a)</sup> clinical reasoning to clarify spiritual pain consisted of six concepts of care: determining level of readiness, accepting patients as they are, establishing therapeutic relationship with patients, searching for appropriate intervention, allowing patients to grieve, and preparing for timely intervention.

The care process continued with clarifying patient's spiritual pain through clinical reasoning. <sup>b)</sup> Intervention and evaluation of spiritual care consisted of two concepts of care: integrating care, team debriefing. Spiritual care is considered to be completed when home visiting nurses intervene in the spiritual pain which was clarified by clinical reasoning and review assessment of their intervention.

Sub category: Clinical reasoning to clarify spiritual pain

Home visiting nurses provided spiritual care for patients with advanced cancer through clinical reasoning to clarify spiritual pain. Clinical reasoning should be continued throughout the process for achieving spiritual care.

Determining level of readiness:

Before conducting an intervention concerning spiritual pain, nurses needed to determine how much the patients accept their own death and are ready for death. Participant described how important hope (to continue living) was to their patients:

*I am concerned about how patients accept their illness and what they want to do from now.(PC)*

Accepting patient's as they are:

Patients in their terminal phase sometimes were upset due to uneasy and disturbed feelings from their spiritual pain and released their anger on the nurses. Home visiting nurses did their best to understand and accept such patients. Some of participants remarked:

*A patient burst into a rampage with a lot of tubes, which she hated to be inserted.(PC)*  
*I am doing my best to understand and*

*accept patient's worry and concerns even though it looks impossible, and examine if I can resolve those concerns.(PH)*

#### Establishing therapeutic relationship with patients:

In order to encourage patients to realize their true wish and wants at their final phase of life, nurses need to establish therapeutic relationship with patients as early as possible. One participant suggested:

*I try to talk about myself first, my personality, background, and experiences, in order for patients to feel comfortable to talk about themselves. I try to find something in common with patients to talk about.(PD)*

#### Searching for appropriate intervention:

When intervening in the spiritual pain of a patient, home visiting nurses spent a lot of time questioning and exploring repeatedly to determine what the patient wishes entail. A number of the home visiting nurses emphasized the importance of allowing the patient's feeling toward the family members to be expressed. The following are examples:

*I try to take a look at what the patient wishes the most and support them to realize it. I prioritize where and how the patient wants to face the end.(PG)*

*I tend to concentrate on giving care to the patient, but I think it is also important to listen to the patient's feeling toward surviving family.(PH)*

#### Allowing patients to grieve:

It is important for home visiting nurses to understand that there is impenetrable spiritual pain as well and giving patients time for grief to be expressed. One participant stated:

*There are things that we can intervene and cannot intervene. I cannot involve myself into the family business but I can serve patient's wish.(PB)*

#### Preparing for timely intervention:

Even though home visiting nurses recognize the spiritual pain and try to intervene, sometimes the patient refused intervention. However, it is required that nurses respect the patient's will, prepare for intervention in a timely manner. One well-experienced participant remarked:

*I quickly noticed that the patient had spiritual pain. When I tried to intervene, she smiled and said, "Don't ask me." but*

*I could see her suffering and understood that she did not want to become what she is now, so I asked her "What is your real feeling?" I started intervention with her husband's cooperation and cancelled to be admitted to palliative care unit. She died at home. If I did not intervene, she would have been admitted to a hospital. Basically those who stay at home and use home-care service wish to die at home.(PA)*

#### Sub category: Intervention and evaluation of spiritual care

Home visiting nurses face the spiritual needs of people. They provide the optimal spiritual care by integrating their experiences of basic care for dying people at home, support for family carers of dying people, and clinical reasoning to clarify spiritual care. After the patient's death, a number of home visiting nurses realized the patient's spiritual pain and learnt from others by team debriefing concerning achieving spiritual care.

#### Integrating care:

Nurses need to realize that they are in the position of being able to intervene in the spiritual pain because they have a more holistic understanding of the patients' physical, psycho-social aspects than other health professionals. One participant asserted:

*I think home visiting nurses, who provide care at home, can hear the patient's words that are difficult for patient to say much more than other professionals and family members. We can look at the patient's background and ease their suffering holistically.(PE)*

#### Team debriefing:

In addition, nurses can be involved in the terminal phase of patients only for a short time. Patients can die before the nurses notice the spiritual pain, which can be recognized in the team briefing afterward. One participant recounted:

*Home-visit nursing care rarely starts at the early stage but start when the patients are already at their terminal phase. We usually do not have enough time to have a deep relationship with them, and I often realize patient's spiritual pain when we review our care in the team debriefing.(PH)*

#### **Discussion**

This study revealed home visiting nurse's spiritual care process based on end-of-life total care which was created by basic care with limited resources, support for family carers, and intervention with clinical reasoning to clarify spiritual pain. Spiritual care is achieved by review assessment of these process for intervention.

The process of achieving spiritual care was closely related to the nursing process which consists of assessment and diagnosis, planning, intervention, evaluation (Fig. 1). Nurses should provide appropriate spiritual care using the nursing process and clinical reasoning.<sup>17</sup> In this study, determining level of readiness, accepting patients as they are, establishing therapeutic relationship with patients, searching for appropriate intervention on "end-of-life total care" belongs to assessment and diagnosis. The allowing patients to grieve, preparing for timely intervention belongs to planning, and integrating care is included in the intervention. Team debriefing on end-of-total care is necessary for home visiting nurses, which is applicable as an evaluation. Appropriate debriefing allowing team collaborating with recommendation for relatives and carers to appropriate referral is recommended.<sup>18</sup>

Access to a home-based program for end-of-life care increased the possibility of dying at home when compared to usual care.<sup>19</sup> this could include appropriate spiritual care. However, even if nurses believe that spiritual care is important, they lack confidence and often do not receive adequate training for spiritual care.<sup>20,21</sup> Also, nurses should not provide spiritual care without competence and confident.<sup>22</sup> A previous research study reported that 25% of families of patients who had been admitted to palliative care unit answered that the patient received spiritual care but 70% of them think the care by doctors and nurses was not helpful.<sup>5</sup> This could be due to not being specialists in spiritual care. As seen in this study however, the participants undertook spiritual care by being available to the patient, not simply by undertaking the delivery of care, which is also consistent with literature.<sup>23</sup> Few home visiting nurses have experience of working in palliative care units, and lack educational

preparation concerning spiritual care. In addition, home visiting nurses should establish credibility well at the first visit, then provide adequate spiritual care in the limited nursing time available. Similar barriers were also reported in a qualitative meta-study on the role of spiritual care in end-of-life and palliative care and included lack of time, professional educational needs and personal, cultural and institutional factors.<sup>24</sup>

In order for home visiting nurses to provide appropriate spiritual care, they require an understanding of spirituality and how this may be affected by illness, injury or disease to best support patients' spiritual needs.<sup>22</sup> It is essential to prepare a care model and conduct educational programs which clarify the process and details of spiritual care. The care model given in this study consisted of some elements seen in McSherry and Jamieson<sup>20</sup> study for example, demonstrating respect, supporting patients and families, and providing relief from suffering. However, the model in this study included the use of clinical reasoning to clarify spiritual pain, undertaken alongside the nursing process. When undertaking the nursing process, the need for on-going, informal, individual assessment of spiritual needs of the patient utilizing the members in a multidisciplinary team is considered essential.<sup>25</sup> Compared to spiritual care in general wards where there are influences of other nurses and healthcare professionals, the spiritual care by home visiting nurses does not indicate any external factors and the care was provided by the nursing competency of individual nurses.<sup>26</sup>

### Study implications and limitations

The data in this study described spiritual care undertaken by experienced expert home visiting nurses. The study revealed the process from building a trusting relationship with patients and families within a short period of time and dealing with their spiritual pain while providing end-of-life total care within a limited time. The participants were eight home visiting nurses from a limited region in Japan, however, the obtained data were rich and saturated. At the scene of home-visit nursing, spiritual care is not



influenced by other staff but by nursing practical skill itself. Therefore, it is suggested that home visiting nurses should develop their practical skills for their spiritual care to enhance the care quality and QOL for people at their final phase of life.

The findings are useful for home visiting nurses who have little/no experience of spiritual care or end-of-life care to understand the assessment method of spiritual pain and the process of working with the patients. However, the study lacks information concerning detailed intervention methods. Further research is needed to investigate detailed intervention methods as well as comparison with hospital-based nurses in total end-of-life care.

### Conclusion

This study revealed that home visiting nurses provide spiritual care based on end-of-life total care and the care process was created by clinical reasoning. Home visiting nurses need opportunities for learning about clinical reasoning concerning spiritual pain to achieve end of life spiritual care. Future research recommendations include the use of quantitative research methods, larger sample size testing this model of care and comparing home visiting nurses with hospital based nurses in total end-of-life care, both nationally and internationally.

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### Conflict of interest

The authors declare no conflict of interest.

### Author contributions

A.T. contributed to the design of this study

and analysis; C.N. performed data collection, analysis and prepared manuscript; R.M. supervised the analysis and critically reviewed the manuscript. All authors read and approved the final manuscript.

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