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End of Life Care and Terminal Care for the Elderly Performed by Care Workers and Nursesin Japanese Nursing Homes

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ABSTRACT

Purpose: The purpose of this study was to identify and clarify nurse and care worker attitudes and approaches toward terminal care provided to nursing home residents. **Method:** Using the KJ method, a qualitative approach, seven nurses and seven care workers working in a nursing home for the elderly were interviewed about end of life care and terminal care. **Results and conclusions:** After analyzing content from the interviews with nurses and care workers using the KJ method, we extracted seven symbolic keywords.Nurses defined terminal care at nursing homes as [care geared toward various types of terminal phases], [coordination with care workers], [anticipating and addressing pain], [family-like care] and [care that considers the elderly as a whole]. Nurses also approached terminal care while experiencing [difficulties understanding the terminal stage], and realized that this is an [era in which society provides terminal care]. Care workers defined terminal care at nursing homes as [end of life care in the nursing home], [performing care that does not rely on aggressive medical treatment], [care that maintains human dignity], and [care that fosters a sense of family-like unity among care workers]. At the same time, care workers felt [the limitations of care and feeling conflicted] and recognized the [need for younger staff education and training], and desired [third party evaluations] of terminal care. With regard to approaches to terminal care shared by nurses and care workers, both experienced worries about the provision of care specific to their profession. In terms of methods of terminal care, both types of workers exhibited approaches that stressed the need for coordinated care, interacting with the family members, interacting like family members, and care that values the individuality of the elderly person. A characteristic of the nurses' approach to end of life and terminal care was their focus on "palliative care for pain," while care workers focused on end of life care leading to
"a natural death."

Keywords : End of life care, terminal care, nurses, care workers, nursing home

1.Introduction

According to the Ministry of Health, Labour and Welfare, Japan's aging rate was 22.7% as of 2011 [1]. Given this situation, the 2006 Revision of Nursing Care Benefits implemented a "LTCI-point addition for severity" to account for the severity of conditions of residents at special nursing homes for the elderly (hereafter referred to as "nursing homes"). Also established was an "LTCI point addition for deathbed care" when certain criteria are met. This point addition system is in its early stages, however, and reflects the fact that deathbed care is a new type of care being practiced by nursing homes.According to a report by Ogusu [2] on the subject of approaches to terminal care at nursing homes, when the intentions of care in the terminal stage are ambiguous, care workers and nurses have no choice but to fumble their way through care. This is often accompanied by an indescribable sense of inadequacy, particularly when care ends upon a resident's death. This likely reflects the hesitation that nurses and care workers feel toward terminal care at nursing homes. Given this situation, adjustments need to be made to the working environment to allow for terminal care to be performed at nursing homes without confusion among employees. According to Hockyley [3], terminal care in hospitals is highly developed in Britain, yet at nursing homes, the

difficulty of establishing policies for terminal care (e.g., cardiopulmonary resuscitation) and low retention of care staff impacts care. Since many elderly experience their terminal stage in nursing homes in developed countries, the establishment of guidelines (tools) that serve as a reference for terminal care in nursing homes is being suggested. Many studies on terminal care in Japan have focused on cancer, and only a few studies have addressed terminal care in nursing homes. Thus, this study aimed to clarify the state of terminal care being performed by nursing staff and care worker staff in nursing homes as a step towards improving the quality of end of life and terminal care at nursing homes in Japan.

2.Objectives

The purpose of this study was to clarify approaches to end of life and terminal care by nurses and care workers for elderly with care needs living in nursing homes in Japan.

3.METHODS

3.1. Definition of terms

Hiroi defines 'terminal care' as "care for both physical and mental dimensions that is based on a consciousness of preparing to meet death peacefully, once it is anticipated that the terminal stage is near." [Hiroi 2000] In this study, Hiroi uses the same definition for 'terminal care' as for 'end of life care.'

3.2. Participants and analysis

- Data were collected from July 19, 2012 to September 25, 2012.
- Seven nurses and seven care workers with at least three years of experience in end of life and terminal care participated in the study. Personal interviews were conducted using pre-determined guidelines and the results were analyzed with the KJ method. Interviews were approximately 60 minutes long. Interview contents were recorded while being mindful of participant privacy and taking care not to interfere with the daily practices in the nursing home.
- Through the interviews, information on participant characteristics (e.g., age, sex, qualifications, experience), attitudes and approaches to care, and care methods were obtained. Interview questions were validated through pre-tests. After the interviews, the contents were summarized, and the research cooperator confirmed the content credibility and the original intention of the answers to the interviewees. Question labels were set as simple sentences to allow for ease of understanding and to ensure only one possible interpretation by the interviewees.
- Interview questions were carefully read and analyzed according to the KJ method of investigation, and the credibility was secured by the research cooperator. After carefully reading the content ,we extracted question labels along with the research purpose such that only one meaning was paired with each the label sentence. Labels with one sentence per meaning were extracted, through the research objective. One label for each of the seven groups was created as a symbol representing that specific content.

Table 1. Participant characteristics

Case No.	Occupation	Sex	Age	Experience (years)
1	Nurse	F	50s	10
2	Nurse	F	50s	15
3	Nurse	F	40s	3
4	Nurse	F	50s	15
5	Nurse	F	50s	15
6	Nurse	F	60s	25
7	Nurse	F	40s	10
1	Care worker	F	50s	30
2	Care worker	F	50s	20
3	Care worker	F	30s	10
4	Care worker	F	30s	10
5	Care worker	F	40s	20
6	Care worker	F	40s	20
7	Care worker	M	40s	20

4. ETHICAL CONSIDERATIONS

This study was approved by the ethics committee of Meiji University of Integrative Medicine.

5. RESULTS AND DISCUSSION

5.1. Approaches to care by nurses

(1)Anticipating and performing palliative care for pain

Some of the labels acquired through interviews with nurses included "the desire to provide care in a positive fashion to support terminal elderly," "the type of terminal care that is thoughtful and anticipates," and "care that is important for creating an environment that alleviates the pain of terminal elderly." Nurses strived to search for methods to alleviate the pain of elderly residents, and anticipated and performed care that alleviates such pain. Henderson [5] stresses "peaceful death" in nursing, and care that is rich in anticipation-like attention reflects [anticipating and performing palliative care for pain], which supports the concept of "peaceful death" for which Henderson aspired.

(2)Care that considers the elderly in their entirety

Some of the labels that were acquired through interviews with nurses included "the desire, based on medical perspectives and the view that aging is a period of ripening, to carry out terminal care by considering the elderly as an individual whole" and "regarding terminal care as an extension of daily living." That nurses considered the elderly in their entirety reflects Nightingale's threefold interest as introduced by Usui [6], i.e. that nursing involves "an intellectual interest in the case," a "heart-felt human interest in the case," and a "practical and technical interest in the case." Nurses view their work at nursing homes as an extension of support of daily living, and perform [care that considers the elderly in their entirety], caring for their physical, psychological, and social needs.

(3)Family-like care

Some of the labels that were acquired through interviews with nurses included "in cases where elderly persons with no immediate family members cannot make decisions about the terminal stage on their own, I feel sorry for the patients because distant relatives make the final decision about the terminal stage instead of the elderly (they cannot decide whether to die at a hospital or die at a facility)" and "would like to have the resident die with his/her intentions respected and with his/her family around." Elderly with no place to go and those with complicated care-related issues are admitted to nursing homes. As a result, nursing staff attempt to play the role of family for those with no family, or, when family is near, they support the family while providing terminal care. According to Henderson [5], nurses are permitted to make decisions in place of the patient. However, in cases in which terminal elderly are in a declined physical state and cannot voice their intent, or, even if nearby, the family cannot decide what is best for the resident, nurses and care workers collaborate to support the family, and for elderly without family, nurses act as a substitute for the family in decision-making, and practice [family-like care].

(4)Difficulties understanding the terminal stage

Some of the labels that were acquired through interviews with nurses included "when elderly patients are close to death, nurses who have long-time experience working in hospitals want to immediately administer drip infusions, a medical procedure" and "at the stage when death is near, the difficulty judging whether elderly should be sent to the hospital to make them comfortable when they are in pain." Nurses performing terminal care experience difficulty making judgments about care during the stages of physical deterioration and various terminal symptoms. Lynn [7] sets forth three kinds of end-of-life care. The first involves maintaining the vital functions of cancer patients, which all of a sudden worsen, leading to patient death. In the second scenario, organ function is reduced secondary to heart failure, improves with treatment, but continues on a downhill course until the patient dies. In the third scenario, dementia and senility are not markedly changed, yet the patient dies from pneumonia. Lynn further states that predicting death within six months is difficult. The point of terminal care is not treatment or extension of life, but rather peacefully meeting death. However, nurses put in that position have difficulty grasping the minute changes that occur in terminal elderly and making judgments, and thus experience [difficulties understanding the terminal stage].

(5)Care geared toward various types of terminal phases

Some of the labels that were acquired through interviews with nurses included "it is important for staff to face death in terminal care" and "the scent of death arises as death approaches, thus cleanliness is an important aspect of care." Nurses provide terminal care that values the elderly individual's personality, while providing supportive nursing for symptoms and minimal medical treatment for elderly close to death. Murai [8] states that rather than carrying out all possible treatments, terminal care in facilities means approaching care with the mindset that this is the last stage and that more useful approaches than medical treatment are available, and that specialists need to approach care as care leading toward a meaningful end. Nurses are thought to stress [care geared toward various types of death], which is geared toward the elderly person's death based on the acknowledgement that this is the terminal phase.

(6)Era in which Japanese society provides end of life and terminal care

One label acquired through interviews with nurses was "rather than at home or at a hospital, an era which stresses elderly receiving care at a facility provides a

glimpse into the current situation of elderly." Since the revision of Japan's LTCI to establish a point addition for end of life and terminal care in 2006, nurses consider performing terminal care within the insurance system to be a reflection of contemporary trends. By accepting deathbed care of the elderly in the context of an [era in which Japanese society provides end of life and terminal care], in social terms, nurses provide care to the elderly who live out their last days in facilities.

(7)Respect the special skills of care workers

Some of the labels that were acquired through interviews with nurses included "desire to avoid putting too much emphasis on care based on experience, although both care workers and nurses are busy with duties" and "nurses want to cooperate to establish the special skills of care workers." Assessing physical and mental health in terminal elderly patients requires a background in science as well as specific knowledge of anatomy and physiology. Sasuga [9] suggests a need for nurses to support care workers in providing terminal care at facilities. This can be taken to mean that it is necessary to [respect the special skills of care workers] in order to provide high quality care that allows terminal elderly to approach death while maintaining their personalities.

5.2. Approaches to care by care workers

(1)End of life care in the nursing home

One label acquired through interviews with care workers was "increasing instances in which elderly desire to reach the end of their lives at facilities rather than hospitals." The interviews showed that care workers expect patients requiring end of life care for terminal care in nursing homes to rise. Okamoto [10] states that the number of terminal elderly who choose to die in facilities, rather than in hospitals or at home, is predicted to rise due to the establishment of the LTCI-point addition for End of life care in nursing homes. It is expected that care workers are aware that nursing homes are a place for the elderly to die, and consider terminal care as [End of life care in nursing homes].

(2)Care not dependent on aggressive treatment

Some labels acquired through interviews with care workers were "desire for elderly residents to eat at least a little and continue living" and "because we don't understand much about medical care, we strive to ensure that they are eating, because we want elderly residents to live longer." Care workers provide care aimed at supporting dietary intake as a part of their daily care of residents. Eating is directly linked to the maintenance of vital activities, and care workers fear that the elderly will die if they do not eat. Conversely, labels acquired through care worker interviews such as "care that supports a peaceful death" and "striving for care that, in the end, allows for the elderly to naturally expire," suggest that care workers work toward understanding the physical stages of terminal care when death is approaching, provide support for eating as part of daily life and watch over states in which patients cannot eat as part of a natural course, in order to offer care that supports a peaceful death. This represents [care not dependent on aggressive treatment]. Hiroi [11] states that terminal care at nursing homes is not terminal care in the sense of the medical model, but rather welfare terminal care in the sense of the living model. Even as they support eating as part of support for life, and feel that they want residents to eat, care workers practice [care not dependent on aggressive treatment], which quietly watches over residents who reach a point when they can no longer eat.

(3)Care respectful of human dignity

Labels obtained through interviews with care workers included "performing care by scoping out what is being desired by residents from various angles" and "the need to maintain a person's dignity when performing excretion care." Similar to daily care, care workers delicately provide toilet care support, which forms part of a resident's physiological needs. In the terminal phase, people are placed in situations in which they must rely on others for support of excretion care, and care workers spoke of the importance of care that preserves the human dignity of the elderly. This reflects the findings of the report on Elderly Care in 2015 published by the Study Group on Elderly Care in 2003 [12], which states with respect to elderly care that there is a need to provide services that allow for the preservation of mental independence and dignity of the elderly. This suggests that providing [care respectful of human dignity] is a policy of terminal care.

(4)Sharing a sense of family-like unity among facility staff

One label obtained through interviews with care workers was "deepening relationships with staff, residents and resident families through terminal care." Care workers develop strong relationships with residents and their families through the provision of long-term daily care. A characteristic of nursing homes is that elderly who lack family with whom they can live, or who have no family caregiver, have lived there since the enactment of the Public Aid for the Aged Act. According to a report by the Health and Welfare Statistics Association [13], on average, many residents in average nursing homes live at these facilities for more than five years. By interacting with long-term residents, acting as a substitute for elderly without immediate family, and providing living care, care workers practice terminal care with a [sense of family-like unity among facility staff].

(5)Limitations of care and feeling conflicted

Some labels obtained through interviews with care workers included "seeing death as defeat, and fighting to win rather than lose even if they know that death is near" and "feel limits and anxiety regarding care that can be provided in terminal care," Death is an unknown world--one that those who provide care have not experienced. As a result, with respect to the support they provide, care workers feel conflicted and are faced with the limitations. Deeken [14] writes that, while one cannot experience death in advance, considering death as a very real problem, investigating the true meaning of life and death, and acquiring mental attitudes to prepare for the death of self and others with a determined consciousness, is, from many perspectives, the most necessary education. Care workers providing care in such situations experience the [limitations of care and feel conflicted].

(6)Need for staff education and training

Some of the labels obtained through interviews with care workers included "the reality of death cannot be conveyed to young staff—there is disconnect in mindset" and "studying to confront life in order to observe living in the terminal stage." This suggests that, in social terms, deathbed care at facilities has begun, and educational efforts that utilize reflections on past terminal care to improve future terminal care are necessary to develop care workers' specialized skills. Care workers providing terminal care seek education and training. Given the institutionalization of deathbed care at nursing homes, care workers, who form part of the facility staff, desire to study about deathbed care. According to Hiroi [11], currently in Japan, views of life and death itself are becoming hollow, and this is especially pronounced with younger generations. As there are many young care workers at present, this indicates [the need for education and training of young staff] involved in terminal care.

(7)Evaluation by society

One label acquired through interviews with care workers was "undergo evaluation of terminal care by third parties and through information disclosure." Incorporating the objective views of third parties, who are unrelated outsiders, into terminal care at nursing home facilities newly established in Japan, makes it possible to confirm the quality of terminal care in social terms as well, and aim for improvements in care worker specialization.

6. ACKNOWLEDGEMENTS

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