Peaceful end of life as seen by nurses involved in end-of-life care at group homes for older adults with dementia

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I. Introduction

In a Japan Group Home Association survey (2013), 50% of older adults with dementia had level II independence degree in daily living for the demented elderly at the time of joining a group home (GH), and 36% left the GH between one and three years later, 40% to be admitted to a hospital and 24% because of death[1]. According to a survey of long-term care benefit expenditures by the Japanese Ministry of Health, Labour and Welfare, benefits for end-of-life care (EoLC) doubled from 323,000 days worth of care in FY 2009, the year the system was adopted, to 684,000 days worth in FY 2013.[2] In a 2006 survey by the Japan Group Home Association, 63.9% of family members using GHs wished for the GH as their place for EoLC[3]. In a survey by Nagata *et al.*[4] on GH representatives and family members of GH residents, EoLC was the type of care most wanted to both give and receive at GHs. As there is a strong social need for EoLC at GHs and as this stage continues to occur more frequently at GHs, quality of EoLC at GHs must be examined.

Ruland *et al.* (1998) presented the concepts comprising a peaceful end of life as the patient being without distress, feeling comfort, being respected, feeling calm, and having loved ones nearby, and stated that the outcome was the caregiver achieving satisfaction with care by helping the patient realize their wishes[5].

Yanagihara (2002) explained that, because being employed in a job to create a good death disrupts one's view of life and death and the caregiver him or herself also experiences the harsh reality of facing the loss of the patient, achieving a good death for the patient can lead to greater understanding of humanity, a sense of lives resonating with one another, and the positive experience of putting concepts into practice[6]. The key to EoLC can be said to rest in the circular relationships of the dying individual, his or her family, and the caregiver. Studies have previously been conducted to examine peaceful end of life in cancer patients and patients in palliative care wards[7][8][9], but not in older adults with dementia in GHs for older adults with

dementia or other nursing care facilities. As EoLC for older adults with dementia at GHs is expected to increase, we it is important to incorporate concepts for a peaceful end of life to increase the quality of care at this stage.

We determined that there is a need to clarify the characteristics of older adults receiving EoLC in a GH, the EoLC being provided there, and the attitudes of caregivers using concepts of a peaceful end of life. Medical care is an essential part of EoLC. We therefore surveyed nurses acting as care staff on the characteristics of older adults who died at GHs and their EoLC.

II. Purpose

We focused on nurses acting as care staff and aimed to clarify the characteristics of older adults dying at a GH, the EoLC being provided there, and peaceful end of life in order to gain hints for improving the quality of EoLC.

III. Methods

1. Study design

This study was a self-administered questionnaires survey.

2. Survey method

Questionnaires were dropped in the mailboxes of GHs between August and November 2014. A total of 1000 GHs covered for EoLC by insurance in August 2014 were randomly extracted from the Welfare And Medical service Network system (WAMNET). A study participation request was mailed to the GHs addressed to the director and nurses, and the nurses carrying out EoLC were asked to complete the questionnaire. A total of 294 responses were received. Of those, 261 were valid, as 33 responded that they did not have experience with EoLC at the GH.

3. Questionnaire composition

As their personal attributes, nurses were asked for their number of years of experience, type of employment, and experience providing EoLC to GH residents.

As characteristics of older adults with dementia approaching EoLC, nurses were asked the age, cause of death, length of stay at the GH, and duration of EoLC of residents. Questionnaires also included an open-ended question about the symptoms seen in the end-of-life stage and EoLC provided and a four-point scale question on peaceful end of life with an open-ended space for writing the reasons. Fourteen questions were composed based on the theory of peaceful end of life by Ruland *et al.* (1998) that were scored on a four-point scale.

4. Data analysis method

The data was tabulated normally and t-tests were performed to determine the relationships with peaceful end of life.

Responses to open-ended questions were summarized and separated by meaning, and then categorized into common groups. When categorizing data, we received advice from a researcher in gerontology.

5. Ethical considerations

Study participants and GHs were explained that the individuals and GHs would have their anonymity protected, and that participation was voluntary and that no detriment would incur should they choose not to participate. They were also assured that data obtained would not have individual identifiers and would be managed carefully upon publication of the study results. The study protocol was approved by the Seirei Christopher University ethics committee.

Ⅳ. Results

1. Personal attributes of nurses

The employment status was employed at a GH for 240 nurses (93.2%), of which 181 were employed full time (70.2%) and 59 were employed part time (22.9%). Six (2.3%) were employed at an outreach nursing care station and two at a hospital (0.8%). The length of experience was 10 years or more for 82.1% of nurses. Nurses had experience providing EoLC at a GH to 5.7±5.2 residents.

2. Characteristics of older adults receiving EoLC at a GH

The type of dementia of older adults spending their final days at a GH was Alzheimer's disease in 161 residents (61.7%), vascular-type dementia in 51 (19.5%), dementia with Lewy bodies in nine (3.4%), frontotemporal dementia in three (1.1%), and mixed dementia in 20 (7.7%). The independence degree of daily living for the demented elderly at the time of moving to the GH was I for eight residents (3.1%), IIa for 46 (17.6%), IIb for 57 (21.8%), IIIa for 78 (29.9%), IIIb for 34 (13.0%), and IV for 26 (10.0%). The cause of death was old age for 148 residents (59.4%), heart failure for 45 (18.1%), pneumonia for 20 (8%), and cancer for eight (3.2%).

The mean age at death was 90.4±8.4 years, and mean length of residence was 5.1±3.5 years.

Symptoms that determined end-of-life stage (multiple answers allowed) were loss of appetite in 197 residents (75.5%), severe weight loss in 98 (37.5%) persistent fever in 60 (23%), dysphagia in 24 (9.2%), persistent diarrhea in 19 (7.3%), and respiratory distress in 16 (6.1%). EoLC contracts at the GH were signed an average of 41.65±60.7 days before death.

3. Care provided by nurses in the end-of-life phase

Medical treatment provided during EoLC was intravenous drip for 135 residents (51.7%), aspiration for 117 (44.8%), wound treatment for 77 (29.5%), oxygen inhalation for 76 (29.1%), urinary/urethral catheter management for 34 (13.0%), and tube feeding for 20 (7.7%).

The data on EoLC was separated into 862 codes in six categories and 35 subcategories.The category of "Health status assessment" had 12 subcategories such as measurement of vitals, checking fluid intake and output, alleviation of symptoms with pain, prevention of bedsores, drip infusion, suction, and massage. The category of "Care for family members" had two subcategories: support for family members and explanation of illness/symptoms to family members. The category of "Care that maintains the person's individuality" had nine subcategories such as assisting communication, interaction with other residents, listening to or singing music, and creating opportunities for residents to visit their own homes. The category of "Care to maintain daily rhythms" had eight subcategories such as washing, eating assistance, changing body position, and elimination assistance. The category of "Liaison with other professionals" had four subcategories: liaison with doctors, advice to staff, securing a 24-hour contact system, and liaison with visiting nurses.

4. Peaceful end-of-life at a GH as seen by nurses

In response to the question of whether EoLC for older adults at the GH was satisfactory, 172 respondents (65.9%) said 'very satisfactory', 68 (26.1%) said 'satisfactory', 11 (4.2%) said 'not very satisfactory', and five (1.9%) said 'not satisfactory'.

The data on peaceful end of life from open-ended questions was separated into 320 codes in six categories and 26 subcategories.

The category of "Condition during final days" had five subcategories, such as being calm, peaceful, and painless, having a stable physical condition, and receiving insufficient relief from distress/discomfort. The category on "Presence of someone to watch over the resident" had five subcategories including final days watched over by family, final days watched over by both family and staff, final days watched over by other residents, and family members present until the end. The category of "Family's reaction after EoLC" had two subcategories: words of gratitude from family members after death and refusal of family members to be involved after death. The category of "Liaison" had seven categories such as sufficient communication with family members and staff, united staff, close cooperation with doctors, and insufficient communication with doctors. The category of "Level of achievement of care" had four subcategories that included care based on the resident's and family members' wishes, regret when looking back, and could not meet or did not know the resident's intentions. The category of "Environment in the final days" had two subcategories: environment where

the resident is accustomed and has lived many years and EoLC during a natural disaster.

Fourteen comments about peaceful end of life were asked with possible responses on a four-point scale of strongly agree (4 points), agree (3 points), disagree (2 points), and strongly disagree (1 point), and the responses were scored. The comments "The resident was peaceful" and "The resident died with people watching over him/her" scored highly. Comments with low scores of 3 points or less were "The resident did not lose hope," "I was able to convey the person's passing to the other residents and give them information about the funeral, etc." and "I was able to remain involved even after the resident's death and set the next goal."

To the question of whether EoLC for residents at a GH was a peaceful end of life, responses of "strongly agree" or "agree" were grouped as "can be considered a peaceful end of life" and responses of "strongly disagree" and "disagree" were grouped as "cannot be considered a peaceful end of life." T-tests were performed on each of the fourteen comments on peaceful end of life. The results are shown in the table. In the "cannot be considered a peaceful end of life" group, the following comments had significantly low scores: "The resident was comfortable," "The resident was peaceful," "The resident died with people watching over him/her.," "The resident had family and/or close friends nearby," and "I was able to remain involved even after the resident's death and set the next goal."

Table 1. Peaceful end-of-life as seen by nurses

Category	Subcategory	No.
Condition during final days	Calm, peaceful, painless	60
	Stable physical condition	5
	Insufficient relief from distress/discomfort	3
	Sudden death	1
	Illness advanced too quickly	1
Presence of someone to watch over the resident	Final days watched over by family	58
	Final days watched over by family and staff	16
	Good daily relationship between the resident and family members	5
	Final days watched over by other residents	4
	Family members present until the end	8
Family's reaction after EoLC	Words of gratitude from family members after death	41
	Refusal of family members to be involved after death	4
Liaison	Sufficient communication with family members and staff	24
	Staff was united	16
	Close cooperation with doctors	11
	Insufficient communication with doctors	2
	Strong uncertainty in staff	1
	Insufficient explanations from staff	1
	Cannot always achieve a 24 hours a day	1
Level of achievement of care	Care based on the resident's and family members' wishes	23
	Satisfaction with care	3
	Mutual trust with the resident	3
	Could not meet or did not know the resident's intentions	7
	Regret when looking back	6
Environmental	Environment where the resident is accustomed and has lived many years	15
	EoLC during a natural disaster	1
	Total	320

Ⅴ. Discussion

1. Characteristics of participating group homes and nurses

In a Japan Group Home Association survey (2013) on the increase of GH residents, 51.0% of nurses provided EoLC at a GH and the medical care coordination system was utilized through nurses employed at a GH in 39.6% of cases and contracts with nurses from outreach nursing care stations, hospitals, clinics, and other medical institutions in 49.2% of cases[11].

In the present survey, 93.2% of nurses who responded were employed by the GH. Nurses had experience providing EoLC at a GH to an average of 5.7±5.2 residents and most had at least 10 years' experience working at a GH.

2. Characteristics of older adults receiving EoLC at a GH

As the type of dementia, Alzheimer's disease was confirmed in 61.7% of residents. The degree of dementia at the time of joining the GH was mild to moderate in 63.3%. The average age at death was very advanced, at 90.4±8.4 years, and the most common cause of death was old age. Death was likely the result of decline in various functions with advanced age. Residents lived at the GH for an average of 5.1±3.5 years, and it is likely that their various functions declined gradually during this period until they reached the end-of-life stage.

In the long-term care insurance system, coverage of EoLC at a GH for older adults with dementia started 30 days prior to the date of death. In the present study, residents signed an EoLC contract and the period until death varied largely at 41.65±60.7 days, indicating that it is difficult to predict the progress of the final stage of one's life.

3. End-of-life care and peaceful end of life at a group home

Residents had mild to moderate dementia when joining the GH, but their functions gradually declined with advancing age while living at the GH and they lost the ability to eat and move around on their own.

Nurses performed health status assessment on residents and alleviated symptoms with pain with procedures such as drip infusion, wound treatment, oxygen inhalation, suction, and massage. Until the resident's death at the GH, they provided care to maintain daily rhythms and performed care that maintained the person's individuality based on the mutual trust developed over many years at the GH. Nurses cooperated with other nursing care professionals and doctors to enable end-of-life at the GH. Nurses provided explained the illness and symptoms to family members and facilitated their interaction with the resident.

Nurses assessed whether or not residents had a peaceful end of life at the GH based on the presence of someone to watch over the resident such as family, staff, and other residents, whether the condition during final days was peaceful, and whether the environment was painless and relaxed.

Good end-of-life care was also enabled by sufficient communication with family members and staff based on the wishes of the resident and their family members and the staff being united in providing care. Nurses also determined whether or not it was a peaceful end of life from words of gratitude from family members after death. In addition, they reflected on the care they had provided and considered the level of achievement of care to determine whether or not it was a peaceful end of life.

In the peaceful end of life questionnaire as well, the condition during final days and the presence of beloved individuals were linked to a peaceful end of life. Nurses said that peaceful end of life was achieved when they reflected on the EoLC they provided and linked their findings to setting the next goal. This suggests that peaceful end of life was the nursing care goal of nurses and that they provided care aimed at achieving that goal.

Ⅵ. Conclusions

Characteristics of older adults spending their final days at a GH were relatively older age and a longer duration of residence.

To enable older adults living at a GH for many years a peaceful end of life, nurses communicated with nursing care professionals and doctors, alleviated symptoms with pain, and provided care to maintain daily rhythms, care that maintained the person's individuality, and care for family members.

Nurses determined whether or not residents had a peaceful end of life at the GH based on the presence of someone to watch over the resident, the resident's condition during final days, the environment in the final days, and whether or not there was good communication with other nursing care professionals and doctors. They reflected on the care they provided while considering the level of achievement of care to determine whether it had been a peaceful end of life.

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認知症高齢者グループホームでのよい看取り

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キーワード：よい看取り Peaceful end of life、認知症高齢者グループホーム living in dementia elderly persons group home、看取りケア end-of-life care

要約

認知症高齢者グループホーム(以下 GH)でのよい看取りを迎えるためのケアモデルを開発するために、質問紙調査により、GHで看取りを迎えた高齢者の特徴、看取りケア、よい看取りについて、看取りに携わった看護師から調査した。(有効回答率 26.1%) GHで看取りを迎える高齢者は、入居して、平均 5.1±3.5 年で終末期を迎え、6 割が老衰で亡くなっていた。死亡年齢は平均 90.4±8.4 歳と比較的年齢が高かった。看護師が行った看取りケアは【健康状態のアセスメント】【苦痛を伴う症状の緩和】【生活リズムを整えるケア】【その人らしさを保つケア】【家族に関わるケア】【他職種との連携】の 6 カテゴリーあった。よい看取りの要素は、【最期の状態】【高齢者を見守る人の存在】【看取り後の家族の反応】【連携】【ケアの達成度】【最期を迎える環境】の 6 カテゴリーに分類された。看護師はよい看取りをケアの目標としていた。