

Qualitative exploration of Japanese rural citizens' consideration of terminal home care through an educational forum

Ryuichi Ohta MD | Yoshinori Ryu MD | Takuji Katsube MME

Community Care, Unnan City Hospital,
Daito-cho, Unnan City, Shimane, Japan

Correspondence

Ryuichi Ohta, Community Care, Unnan City
Hospital, Daito-cho, Unnan City, Shimane,
Japan.
Email: ryuichiohta0120@gmail.com

Abstract

Background: The need for home care services for older adults is gradually increasing in many countries. In the past, Japanese older adults typically died at home, but the current trend is toward hospital death. Few studies in Japan have explored peoples' viewpoint on home care, however, especially in rural areas. Therefore, we clarified Japanese rural residents' views of terminal home care.

Methods: We conducted a qualitative study of 152 participants who are current or potential caregivers of older adults and who live in the city of Unnan, Shimane Prefecture, which has a large elderly population. An educational forum consisting of presentations and a workshop were used to provide information on terminal home care to rural citizens. A thematic analysis of the workshop's content regarding participants' perceived difficulties related to terminal home care was conducted.

Results: Participants described four themes regarding problems of terminal home care: medical aspects, care burden, health care system, and patient problems. Besides the need for more knowledge of the medical and health system, participants were anxious about the burden of care on their lives and the perceptions of others in their community.

Conclusion: This study is the first report on Japanese rural citizens' views of terminal home care. The findings suggest that the limited use of home care in Japanese rural areas might relate to a lack of understanding of terminal home care and health care systems, a substantial care burden for caregivers, and conflicts between patients and families.

KEYWORDS

educational forum, home care, Japan, rural area, terminal care

1 | BACKGROUND

The elderly population is increasing in Japan, and the availability of places to care for these older adults has become a social problem.¹ The medical model has shifted from a cure model to a care model, in which the focus has become not only the removal of

diseases but also learning to live with diseases. The importance of comprehensive community care has been highlighted in Japan.² Older adults require comprehensive community care to increase their health and life span.³ Caring for older adults in the community requires supporting their physical function, which decreases with age.⁴ However, many older adults have been forced to live

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alone because those in younger generations, who previously would have cared for their elderly family members, are now living apart from them.⁵ Older adults with decreasing independence in daily living owing to a decline in physical function might not receive sufficient care from their families.⁶ However, social health resources are concentrated in urban areas and are few in rural areas—as such, older adults very often do not have sufficient access to home care, and their families tend to struggle with their care.⁷

Having a suitable place for older adults to receive terminal care has become a critical problem in Japan because of an increase in the elderly population. Based on recent statistics, the home death rate was <15% in 2006.⁸ Because of national governmental policy, the number of Japanese hospitals has steadily decreased.⁹ Therefore, it is necessary for an increasing proportion of deaths to take place in the home. However, citizens may not be sufficiently prepared to cope with home deaths.¹⁰ Additionally, inquiry into citizens' ideas about terminal home care is necessary but has not been performed, especially in rural areas.

Unnan City is located in the southeast part of Shimane Prefecture, with a population of about 40 000 and an older population exceeding 33% of the total population and estimated to reach upwards of 50% by 2025.¹¹ However, the rate of death at home is only around 10%, making it well below the national average. It thus appears necessary to promote terminal home care in this area. Unfortunately, sufficient support to this end has not been provided. The citizens' knowledge of terminal home care may also be lacking. In an effort to improve the understanding of terminal home care among citizens in Unnan City, an educational forum was held. Comprehensive community care can be provided more smoothly by promoting residents' understanding of home medical care through educational interventions. Therefore, the purpose of this study was to explore rural citizens' views on terminal home care within the current home care system.

2 | MATERIALS AND METHODS

A qualitative analysis of the content of a workshop on difficulties in terminal home care was conducted. Participants were all residents in Unnan City over the age of 15 who were current or potential caregivers of older adults in their homes. In Unnan City, there are 30 autonomous communities in which each citizen considers and acts on issues regarding their lives and health. We provided information about the educational forum to the autonomous communities through an invitation letter. We mentioned in the letter that the data gathered at the forum would be used in research to improve Japanese home care. Each resident group had one preexisting delegate; the delegate for each group provided the group with details about the educational forum in their group's meeting and recruited 3-5 participants from their group. A total of 152 participants took part in the educational forum, and 101 provided valid questionnaire data before attending the forum. The questionnaire covered background data of the participants: age, gender, living location, present caregiving situation, and working situation.

2.1 | Educational forum on terminal home care

The two physicians responsible for home health care at Unnan City Hospital provided information on the current status of death at home in Unnan, the current home care system, and prospects of terminal home care through an interactive lecture. Subsequently, a home care nurse from a home care nursing station in Unnan City provided information on the present situation of home care nursing in Unnan City through an interactive lecture (Table 1), after being provided with the information by the researchers. After the information was provided, participants were divided into 26 groups, and a workshop was conducted. The two physicians and the home care nurse did not participate in the workshop. Each group was given one of four themes, namely, "my own terminal home care," "terminal home care of family members living nearby,"

TABLE 1 Content of the interactive lectures

Lecturer	Content	Explanation
Physician	Current trends in Japan	The population is aging, and the death rate is gradually increasing. The ability of Japanese medical institutions to accommodate patients will decrease. Increased home terminal care will be needed in the future.
	Medical services that can be given through terminal home care	Physicians, nurses, and home care workers can provide many kinds of care similar to hospital care to terminal patients at home.
	Financial cost and financial/municipal support available	Japanese long-term care insurance can provide financial support for terminal home care. There is a clerk responsible for advising on home care at city halls.
Nurse	Work of home care nurses and home care workers	Home care nurses can assess home patients' condition and provide appropriate care based on advice from physicians. Home care workers can provide different types of care for patients, such as personal hygiene care and home cleaning.

TABLE 2 Characteristics of participants in the educational forum

Gender	N = 101	Percentage
Male	57	56.4
Female	44	43.6
Age group		
30s	10	9.9
40s	12	11.9
50s	20	19.8
60s	35	34.7
70s	24	23.8
Presently caregiving	47	46.5
Presently working	60	59.4

“terminal home care of residents living nearby,” and “terminal home care of family members living far away.” Group assignments were carried out in advance based on the participant list. First, participants’ names were ordered according to age, from youngest to oldest. Then, small groups were created, each consisting of five to six participants of varying ages (ranging from their 30s to 70s). Medical staff such as hospital physicians and nurses joined the groups as facilitators, and each group provided ideas on the “problems” based on each theme. The duration of the workshop was 40 minutes. For the first 10 minutes, the participants wrote their ideas on sticky notes and put them on the center of the table. Then, the participants shared their ideas with the other group members in the last 30 minutes. At the end of the workshop, participants had time to share each group’s ideas with the other groups that discussed the same theme.

2.2 | Qualitative analysis

Ideas suggested by participants in the workshops were considered as qualitative data. A thematic analysis was used to extract factors related to problems in terminal home care.¹² Thematic analysis consists of the following phases: (a) familiarization with the data; (b) generating initial codes; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; and (f) producing the report, including a selection of illustrative data and quotations. To explore the rural citizens’ views on terminal home care within the current home care system, we analyzed transcripts of the forum meetings.

RO and YR were the physicians at Unnan City Hospital in charge of home care, and presented the issues regarding home care in this educational forum. TK was the hospital clerk. RO and YR independently coded the transcripts (the sticky notes) and then checked for agreement of the codes, discussed the codes and emerging themes, and reached a consensus by recoding or redefining when someone disagreed. To minimize personal bias, the transition from codes to preliminary themes and then to the final themes included frequent discussions with the third author (TK), who was a citizen in Unnan. We used an analytic framework including the identification

of key concepts to discover core ideas and to understand how participants view the topic.

2.3 | Ethical considerations

Participants were informed that the data collected in this study forum would be used only for research purposes, both prior to coming to this workshop and before the start of the forum. Questionnaire data were anonymized. Participants were also told of the aims of this research and of how data would be disclosed and their personal information protected; they then provided written consent prior to completing the first questionnaire. This study was approved by the Unnan City Hospital Clinical Ethics Committee.

3 | RESULTS

3.1 | Background data

There were 152 participants in the educational forum, and 101 provided valid questionnaire data (66.4% effective response rate). Among them, 57 were male (56%) and 44 (43.6%) female. In terms of age, participants in their 60s were the largest group (Table 2).

3.2 | Terminal home care problems

As for the results of the thematic analysis, we extracted 16 themes grouped into four categories: medical aspects, care burden, health care system, and patient problems. Table 3 shows each category’s explanation and themes.

3.2.1 | Medical aspects

Participants were anxious that they did not have concrete and detailed images of the kinds of medicine and care that would be provided in their home, as there are various types of home care. In addition, participants were anxious about differences in the quality of home care depending on home care staff. There are shortages of medical staff in Japanese hospitals, clinics, and other medical institutions, and the participants felt that the lack of medical resources was a restriction on increasing the amount of home care. Individuals who wanted to die in their home were anxious about the perceptions of people around them. There were considerable differences in participants’ perceptions of death between the generations. Because of the decrease in home care, most were used to the idea of hospital deaths. The participants were also afraid of changes in patients’ condition, and admitted not having enough knowledge about these conditions.

3.2.2 | Care burden

Participants experienced various kinds of care burden. Most caregivers had busy lives and jobs. They felt that if they had to take care of their family, they would not have enough time and would

TABLE 3 Themes and categories of terminal home care problems

Category	Explanation	Themes	Quotes
Medical aspects	Issues related to knowledge and application of medicine and to long-term terminal home care	Variety of home care	"I don't have clear images of home care, although I can understand the content of home care" (Group 1, Female (F)).
		Depopulation of medical field	"The quality of home care may change because of the quality of the staff, which may lead to poor home care" (Group 3, Male (M)). "In my area, no physicians will be able to do home care" (Group 16, F)
		Concern about perceptions of neighbors	"Although my mother and family hope my mother's death takes place in our home, my relative told me why I should take my mother to the hospital and that I should take her to bigger hospitals" (Group 4, M).
		Anxiety about change in patient's condition	"When people are dying, what kinds of symptoms do they have? As I don't have experience, I cannot imagine the situations at all" (Group 7, F).
Care burden	Anxiety about the burden of terminal home care	Time burden	"I have to work and take care of my child. I might not have much time to care for my parents" (Group 9, F).
		Physical burden	"I know that I have to take care of my parents, but I feel that I am not that young, and I also have some diseases that require care. I may not be able to help my parents" (Group 20, F).
		Financial burden	"Both my wife and I work and struggle to survive. If I must pay for home care for my parents, we will end up in a bad financial position" (Group 8, M).
		Home problem	"I did not imagine this situation, so my house is not equipped for home care" (Group 2, M).
		Privacy	"In the past, we knew each other. But now, we don't even know much about our neighbors. Privacy may lead to less collaboration among people in communities" (Group 1, F).
Health care system	Issues related to social systems such as long-term care insurance and social connection	Information resource	"I know the importance of home care, but I don't know where I can get information. I should know about information resources" (Group 11, M).
		Diversity of community	"Our community has many kinds of people, and they have different ideas, which has formed our culture. Some people don't like to accept others" (Group 6, F)."
		Lack of knowledge about medical systems and long-term care	"I have never learned the system related to home care, and cannot learn it because of aging" (Group 4, M).

(Continues)

TABLE 3 (Continued)

Category	Explanation	Themes	Quotes
Patient problems	Issues related to patients' decisions and their relationship with family	Rejection of care	"If my father would accept home care, I would be relieved. But he didn't like strangers coming into his house" (Group 1, F).
		Concern for caregivers	"I don't want to cause stress to my family, financially or physically. If I must accept help, I want to die as quickly as I can" (Group 22, F).
		Readiness for end-of-life care	"It is very difficult to discuss death with family because elderly people might think that we want them to die early" (Group 16, M).
		Relationship among family	"I don't know my parents' ideas because we have not talked much with each other in a long time. We may not have a good relationship. So, I will be confused if I have to take care of them" (Group 12, F).

be stressed. As parents grow older, so do their caregivers. Some caregivers felt that they had become too weak and that they might not be able to effectively care for their parents. The cost of home care was also thought to put a burden on caregivers. Some participants did not know the cost of home care, and the information provided surprised them and caused them to realize that care would be financially taxing. Furthermore, participants worried that their homes were not equipped for home care and that they would have to renovate their homes. In the past, community members shared information about each other. Although rumors can have disadvantages, such sharing of information allowed people to learn of others' difficulties and to help each other when needed. However, as privacy has become more important, individuals no longer share such information.

3.2.3 | Health care system

Participants were anxious about how to collect information about home care. They did not know where to get information. The participants lived in various rural communities, each with its own context. As a result, participants thought that home care could fit within their culture. Additionally, the participants had anxiety about their lack of knowledge of medical systems and long-term care.

3.2.4 | Patient problems

The participants had different characteristics and contexts. Some did not want to depend on others except for their family, even if they could not perform activities independently. However, their rejection of formal home care exhausted their caregivers. Participants were also concerned about caregiver fatigue. They did not want to put stress on their relatives. For terminal home care, individuals must consider both their own and others' deaths. However, in rural areas, discussion of death might be avoided, which can lead to fewer

opportunities for terminal home care. Finally, older adults had different relationships with their family. Those with good relationships could get help from their family; however, for some older adults, receiving home care would be difficult because they had poor relationships with their family.

4 | DISCUSSION

This study suggests that Japanese rural citizens are anxious about the ambiguity of patients' medical conditions, the various burdens that home care might impose on them, the lack of information resources, and a lack of clarity in patients' decision making and sometimes difficult relationships with their family. It is necessary to provide information not only on the medical issues but also on long-term care insurance, as well as to promote further efforts to reduce the physical and financial burden of home care.

In terminal home care, both the patients' will and the will of the family supporting the terminal patient are important. Conflict among them may lead to bad relationships and/or rejection of home care. Additionally, fewer opportunities to discuss terminal home care may lead to poor readiness for end-of-life care.¹³ The various burdens of caregiving on the household regarding time, physical, and financial issues might be considerable, which can hinder proper terminal home care,¹⁴ and may lead to sleep disorders and depression in caregivers.¹⁵ Because of privacy issues, neighbors may have certain difficulties such as not knowing when care and support are needed, as they do not want to invade patients' privacy. In Japan, where the rate of terminal home care is currently low, anxiety about terminal home care is considered a major factor preventing implementation.¹⁰

Regarding the health care system, the study's rural cultural background might explain why people who care for dying family members at home might become highly anxious and sensitive to others' perceptions. Considered from the perspective of the rural community,

the themes “diversity of community” and “citizen’s perceptions” may be specific to rural settings, while the other themes may appear as common themes in all communities. Rural Japanese culture is male dominated, and men in these communities tend to have a high degree of contact with individuals outside of their household.¹⁶ Each community’s norms may be decided largely by specific men in each community, so the community norms may be quite different in each community because these men’s ideas may be various. These interactions may lead to diverse attitudes in the community, even for decisions regarding terminal care.¹⁷ Acting against these norms might lead to interpersonal conflict and in turn burnout,¹⁸ which may prevent promotion of terminal home care in an area with a community norm that elderly people should die in hospitals.¹⁹ Furthermore, the diversity of attitudes may make these problems more complicated because the solutions to this problem are varied, and there is a lack of corresponding resources in terms of medicine and care in each community. Long-term continual terminal home care will change people’s perceptions, but only over time, as the culture is difficult to change.

There was a strong need to provide information on medical aspects related to terminal home care and how to use it. Many studies on home care focus on medical and nursing content¹⁴; there is comparatively little research on caregivers’ anxiety.²⁰ Inadequate understanding of long-term care insurance and home care in Japan might have been another factor preventing implementation of terminal home care²¹; additionally, according to this result, the citizens may not have proper information resources about it. As medical professionals are growing old along with the general population, there is also a possibility of a lack of medical staff in rural areas, and various aspects of home care may confuse citizens. This in turn may increase anxiety around change in a patient’s condition, as citizen caregivers may feel that they may not get enough help from medical professionals when they experience a difficulty in terminal home care. For terminal home care to improve in the future, it is necessary to not only provide information on medical aspects but also discuss concrete solutions to alleviating care burden and providing medical resources from various sources,¹⁵ in collaboration with the government.

One of the limitations of this study concerned the data collection method: Although the data were qualitative, our use of sticky notes to collect data during the workshop likely prevented full exploration of participants’ ideas. Thus, semi-structured interviews should be used in future research to explore the ideas about terminal home care in greater depth. Another limitation is the effect of the educational forum. The two physicians’ and nurse’s presentations may have affected the participants’ comments. To reduce this effect, we tried to present material neutrally and focus solely on conveying the present state of home care in Unnan City.

5 | CONCLUSIONS

Our results suggest that it is necessary to not only provide information on medical aspects of home care and the medical care system

but also offer support for caregivers to cope with care burden and decision making related to terminal home care.

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CONFLICT OF INTEREST

The authors have stated explicitly that there are no conflicts of interest in connection with this article.

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