The experience of providing end-of-life care at home: The emotional experiences of young family physicians

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Abstract

Background: End-of-life care is now a major issue in Japan as a result of the rapidly aging population; hence, the need for fostering family physicians to be engaged in end-of-life care at home is increasing. Studies in the United States and the United Kingdom have shown that physicians feel emotional and moral distress in end-of-life care, and that they develop detachment and dehumanizing attitudes toward patients as a coping mechanism. However, few studies have explored the emotional experiences that family physicians have during home-based end-of-life care. The aim of this study is to explore the emotional experiences of young family physicians in such situations.

Methods: We conducted a qualitative analysis of interviews with family medicine residents or family physicians who had just completed their residency. The interviews were audio-recorded and transcripts were prepared. The coded data were analyzed according to thematic analysis using NVivo 10 software.

Results: Study participants were 12 family physicians of PGY 5–11, with experienced end-of-life care cases of 3–20. Thirteen themes were extracted from the data, which were categorized into five domains: difficulties in end-of-life discussion, emotions of physicians, the role of physicians, communicating with the family, and positivity in end-of-life care. The physicians experienced various emotions and struggles within these domains, but they also felt something positive through providing care for the dying patients and their families.

Conclusion: Family physicians experience various emotional difficulties during end-of-life home care. However, positive emotions at the end of life were also experienced through their care.

Keywords: emotional distress, end-of-life care, family physician, general practice, home care
INTRODUCTION

A rapidly aging society with a growing elderly population has become a major issue in many countries, and Japan is no exception. In 1951, in Japan, 82.5% of people died at home, and only 9.1% died in hospital, but in 2005, 79.8% died in hospital, and dying at home was only 12.2%. However, most Japanese people do not wish to end their lives in the hospital. According to a 2017 survey, among the adult subjects who responded, 69.2% answered that they would like to spend their final days at home.

The necessity to foster family physicians or general practitioners who can comprehensively care for end-of-life patients at home is growing in Japan. It is estimated that by the late 2030s there will be a need for approximately 1.7 times as many home physicians as compared to the current number. Certification for family physicians was established by the Japan Primary Care Association in 2009, and the Japanese Medical Specialty Board was established in 2014 as an independent third-party institution to guarantee the quality of training programs and medical specialists, but the specialized training of general practitioners did not begin until 2018. The general practice training curriculum lists the following as learning goals: understanding patients' and their family's perspectives on health, life, death, and religion that are necessary for establishing palliative care at home; providing appropriate information for patients and family; being able to offer management of pain and other symptoms; grief care; and end-of-life care. It clearly indicates the importance of training in at-home end-of-life care.

Emotional distress and burnout are critical issues among physicians caring for patients at the end of life. Physicians working in intensive care units are at risk of developing burnout mainly because of emotional conflicts with patients and families. It appears that the psychological morbidity and burnout of palliative care doctors are not much greater than that experienced by other specialties, although studies show that emotional exhaustion and depersonalization can be associated with hours of work per week in palliative care. Past literature has shown that physicians and nurses engaged in palliative care feel psychological resistance or dilemma in discussing topics related to death and spiritual issues with patients and their families. Kelly et al. reported that Australian family physicians struggled with honesty when discussing death and prognosis with regard to end-of-life care and when examining the emotional response of patients. One study in Japan reported that many nurses working with end-of-life patients experience an "inconsistency dilemma," wherein the care desired by patients was not being provided, causing the nurses to experience uneasiness, insecurity, and fatigue.

It has been reported that physician trainees involved in end-of-life care in the United Kingdom and the United States feel emotional and moral distress about the unpredictability of end-of-life care. In the study by Kvale et al., a survey of 157 family medicine residents in the United States revealed that young residents experienced severe stress regarding unpredictability and anxiety over caring for dying patients. In another study, physician trainees felt moral distress about the delivery of potentially inappropriate treatments, a poorly defined care trajectory, and the involvement of multiple teams creating different care expectations in end-of-life care. Trainees in the United States felt moral distress about patient autonomy and a fear of lawsuits, which contributed to their moral distress. Moreover, some trainees in the United States developed detached and dehumanizing attitudes toward patients as a coping mechanism, which may contribute to a loss of empathy.

Qualitative research on home-based end-of-life care is scarce, and few studies have focused on the emotional aspects of physicians. A qualitative study of general practitioners in France investigated what resources are available to reduce psychological burden, and listed internal resources as the doctor's practical experience and continuous medical education, personal history, work time organization, and a tacit moral contract related to the referring general practitioners' position. In a qualitative study of health care providers engaged in home-based end-of-life care in China, being unable to provide the service and feeling powerless when facing psycho-spiritual problems were cited as major difficulties. It has been revealed that physicians' communication in end-of-life care differs between Japan and the West, including the avoidance of direct expression and greater consideration for family members. Therefore, evidence from other countries regarding the emotional issues of physicians in end-of-life care may not be directly applied to Japan.

This study aims to examine young family physicians' internal experiences with respect to emotions and struggles experienced in providing home-based end-of-life care in Japan. Through this study, we believe that problems related to the emotional aspects of medical professionals involved in home-based end-of-life care will be elucidated.

METHODS

2.1 Participants and data collection

This study aims to explore the experience of young family physicians or family medicine residents through interviews and analysis of narratives. We selected only young family physicians for the participants because it was assumed that young doctors face more anxieties or emotional distress than skilled doctors when they experience the death of patients because of the following reasons. Many studies have shown that junior doctors experience high levels of emotional distress, including burnout and fatigue, which peaks during post-graduate residency. It is said that this is due to a demanding workload, little autonomy, an unstructured learning environment, and other factors. Thus, we set the inclusion criteria for selecting the participants as follows: participants should be residents in family medicine or family physicians who had completed their residency within a year, and who provided home-based end-of-life care. A family physician here means a specialist who is certified by JPCA (Japanese Primary Care Association) or belongs to a family medicine training program accredited by JPCA. In this study, end-of-life care was defined as the experience of providing end-of-life care and encountering the death of a
patient. It is possible that the differences in end-of-life care between cancer and noncancer diseases may have influenced the differences in the narratives of the participants, but both were defined as end-of-life care and were not specifically separated in this study.

We employed convenience sampling, and the authors’ acquaintances were asked to participate in the study. Because it was thought that the quality of interviews would be higher if the participants had a trusting relationship with the researcher, as they would be asked to talk about their personal feelings in end-of-life care situations. Since the first author (DS) and second author (AO) are family physicians, we listed family physicians (residents) who met the selection criteria among their family physician connections, asked them about their consent to participate in the study by e-mail, and requested only those who were willing to consent. Convenience sampling is often used as a sampling technique for qualitative research, but it is likely to be biased. Compared to the general population, the sampled population in this study consisted of physicians from training programs in the Kanto region of Japan, which may have resulted in a relatively homogeneous training environment. To deal with the bias, we took care of gender balance, and we sampled physicians from three or more training programs. The fact that a trusting relationship had already been established with the interviewers (the authors), was considered a strength in eliciting good quality narratives.

From May 2012 to November 2013, researchers mainly conducted face-to-face individual interviews with physicians, with some participants being interviewed online via Skype®. We decided to conduct individual interviews rather than focus groups because we thought it would be better to give priority to privacy when asking participants to share their personal and emotional experiences. The semi-structured interviews were audio-recorded with the prior permission of the subjects, and transcripts were prepared. Collected data included age, sex, job title, years of experience in home health care, and the number of end-of-life home care cases. Interview items included “How did you feel about your experience in the end-of-life care for end-of-life patients?” “What did you find difficult?” “Was the end-of-life care different at home compared to at hospitals?” and “How did you handle difficult situations, or how do you think you should have handled such situations?”

### 2.2 | Data analysis

The collected data were analyzed by thematic analysis. Before analyzing the data, the transcripts were read repeatedly to thoroughly understand the overall context, and then the main points in the text data were coded. During this process, the words used by the interviewees were retained as much as possible. Codes were then compared for similar and common points, and multiple codes were grouped into categories. The first author (DS) and second author (AO) were independently responsible for the initial coding and analysis. Afterward, the two authors discussed and organized the coding, replacing it with more appropriate codes. Then, the third author (ST) reviewed and confirmed the validity of the overall coding for triangulation. The first and second authors are certified family physicians and have experience in home end-of-life care. They have a belief that they would like to see more end-of-life care at home than in hospitals, but this may also be a bias. The third author is a diabetologist and is currently in charge of a program to train general practitioners. He has no experience in home-based end-of-life care as a physician, but he had the experience of taking care of his own father’s death at home. He has a relatively neutral opinion on home deaths and hospital deaths but expects to see more home deaths. The analytical software was NVivo for Mac, Version 10.2.2.

### 2.3 | Ethics

Ethical concerns included maintaining the confidentiality of the personal and sensitive information revealed in the interviews. The participants were informed of the study’s aim and protocol, and all the participants provided written consent. The study was approved by the Ethics Review Committee of Tokyo-Hokuto Health Co-operative Association (approval number: 48).

### 3 | RESULTS

Twelve family medicine residents or family medicine specialists participated. Table 1 provides a profile of the 12 physicians who participated in the study.

The study included 6 men and 6 women, with an average age of 31.1 years (range: 29–35 years). The time since graduation was an average of 6.9 years (range: 4–11 years). The average experience with home medical care was 3.0 years (range: 1–5 years), and the average number of end-of-life care cases was 9.8 (3–20 cases). All of them had educational support about home-based care, and all the physicians worked in an environment where they had collaborators in providing home-based care. The interviews were 47 min long on average.

The extracted codes and categories are shown in Table 2 and are discussed below. Typical interview texts according to themes are presented in Table S1.

### 3.1 | Difficulties in end-of-life discussion

#### 3.1.1 | Bewilderment with unpredictability

Physicians felt bewilderment by the unpredictability associated with end-of-life care, which involved unpredictability about prognosis and decision making with dying patients. They talked about encountering difficulty in understanding their patients’ wishes, mental resistance when listening to their wishes, coping with changes in the patients’ emotions, difficulty in informing patients about their diagnosis in cases of cancer, and confusion about how to guide end-of-life care at home by correcting patient misunderstanding.
3.1.2 | Difficulties with discussing the final step

Physicians said that although they understood the importance of providing information ahead of time, the evasive attitudes of patients, and resistance of the family with regard to discussing the end of life made the situation difficult.

3.2 | Emotions of physicians

3.2.1 | Fear of caring for end-of-life patients

One physician felt fear and emotional pain when facing the spiritual pain of dying patients. The fear was twofold: the fear of facing patients’ powerful emotions and the fear of not knowing how to handle such situations. The grotesque injuries such as bedsores further spurred the fear.

3.2.2 | Struggles with physicians’ own emotions

Some physicians struggled with the expression of their own emotions when facing patient deaths. While objectively thinking that being emotional would be problematic, the physicians could not hide their emotions and felt frustrated.

It is painful, difficult, and sad to watch patients gradually become weaker while being the recipient of their strong emotions. I worry that I would not know what to do when patients say something to me. In that sense, it is frightening just to go see patients. Yes.

(Physician C)
emotions in a proper manner. I do become emotional, and may tear up. But, another part of me remains calm.

(Physician I)

3.2.3 | Desire for personal interaction

Some physicians felt satisfaction in not being limited to their role of a physician who confirms death but instead being able to have some level of “personal interaction” with the patients. This means communicating and establishing relationships through visiting the patients, not just simply demonstrating as a medical professional. One physician stated that by spending several hours with the patients before their death, it was easier to have personal interaction.

3.3 | The role of physicians

3.3.1 | Confusion about the role of physicians

Some physicians tended to feel dissatisfied when they could only play a role of certifying death regardless of whether it was end-of-life care at a hospital or at home. However, they also felt the importance of announcing death as well as confusion in sharing the role with the nurses.

3.3.2 | Wanting to support individual departure

In at-home end-of-life care, it was relatively easy to select clothing and other items that the deceased liked along with the family members and then orchestrate a suitable departure for the deceased. Some physicians found this meaningful.

When the deceased that I announced is surrounded by their favorite clothes and other items for their departure, I find a joy in that. It is nice to see them meet their end in their own way. There is a joy in seeing people depart in their favorite clothes or uniform from work or something like that.

(Physician C)

3.4 | Communicating with the family

3.4.1 | Being considerate of family members

Physicians respected the emotions of family members and relatives and chose their words carefully when communicating with them. Depending on the context of the relationship with the gathered relatives, some physicians would carefully change the way they communicated.

3.4.2 | Guilt that not enough care was provided to the family

Some physicians felt guilty about not offering enough care or appropriate words to the families. In particular, when the psychological burden and shock were significant for the family, such guilt became more prominent.

I was at a loss when I phoned the patient's son. He did not say anything, so all I could do was to talk about facts, like 'I confirmed the passing' and 'someone will call you later'. I was unable to say the right things.

(Physician E)

3.4.3 | Saved by appreciation from the family

Some physicians felt great satisfaction and relief when the family was appreciative during end-of-life care or grief care visits.

3.5 | Positivity in end-of-life care

3.5.1 | Comfort with end-of-life manners

One physician wanted to develop graceful manners, concerned with “manners during end-of-life care.” Another physician focused on communication and carefully considered the family’s emotions through their external behaviors, suggesting that such manners in end-of-life care could be learned from other occupations, such as nurses.

3.5.2 | Feeling the warm atmosphere at the end of life

One physician felt that, at the moment of death, there was a warm and comforting atmosphere at home, unlike in the hospital. This could be because he or she felt the moment of death was not being as the “end,” but the moment when one could appreciate the spiritual continuity.

There is often a warm atmosphere at the time of the end-of-life care. There is a sense of comfort. I have seen many cases where there is a sense in the air of everyone having done all they could.

(Physician H)

3.5.3 | Appreciation and respect for the deceased

In the solemn moment of death, some physicians first said something to the deceased patient to show their respect. It was an act of...
respect for the deceased and, at the same time, it displayed care for the family members left behind.

First, before confirming the death, I ask the family to come close. Then I say ‘you did a good job’ for the deceased. I notice that many patients appear peaceful. So, I often say ‘they look peaceful. I assume they are happy to be at home’.

(Physician C)

Some physicians touched the body or cleaned the body with nurses to show their appreciation and respect. Some said that such actions were not observed as much at the hospital but happened more naturally at home. In the process of touching the patient and providing postmortem care, emotional care was naturally provided to the family.

4 | DISCUSSION

In the present study, young family physicians experienced various emotions and struggles while providing end-of-life care at home, which were derived from unpredictability at the end of life and their own emotions and roles, and communicating with the family, among other issues. However, positive emotions at the end of life were also observed, such as feeling a warm atmosphere or a sense of appreciation and respect for the deceased.

To the best of our knowledge, this is the first study that focused on the emotional aspects of young family physicians providing home-based end-of-life care, particularly through in-depth qualitative exploration of the small number of participants. There are some previous studies on the roles of family physicians in end-of-life care, suggesting physicians being a good communicators and decision-making support for patients and their families.23-26 A recent review revealed that addressing patients’ social, emotional, and spiritual needs are one of the important roles of primary care physicians.26 Most physicians in the current study mentioned that they were also engaged in the emotional needs of patients or families, which was consistent with previous studies.

The confusion that physicians felt in the present study was similar to those experienced by health professionals engaged in end-of-life care at home in previous studies.27,28 One study reported nurses’ feelings of bewilderment, including difficulty supporting decision making about home care, difficulty incorporating the wishes of the patient, the burden of accepting the death of the patient, and doubt and regret about the care provided.27 In a study of Belgian general practitioners, the participants felt unpredictability about the mandate in deciding and negotiating the final step of life.28 In this study, “difficulties with discussing the final step” was experienced by the physicians. This result may apply to not only family physicians but also all physicians. In a nationwide survey in Japan in 2017, only 27.8% of physicians considered they had adequate end-of-life discussions with their patients near death.29

Umeda et al. compared the awareness level of nurses and physicians with regard to end-of-life care in emergency medicine.30 The awareness of nurses focused on peaceful death, respecting individuality, and incorporating the wishes of the family. In comparison, the awareness of physicians focused on the value of interaction with the family, peaceful death, better medical team collaboration, and difficulty making decisions in regard to treatment policy. With regard to end-of-life care, both physicians and nurses wanted to respect the wishes of the patients and family members, whereas physicians were more concerned with treatment policy and the team medicine system. Although the setting of emergency medical care is different, in all end-of-life care, regardless of location, physicians and nurses tend to respond to the needs of patients and family members.

Physicians’ resistance to unpredictability and anxiety over death affects the care of end-of-life patients. In the previous study, physician trainees who experienced more severe anxiety about death experienced more severe anxiety about caring for dying patients.10 In our study, physicians discussed their struggles with expressing their emotions and revealed that personal experience with the death of loved ones might affect their anxiety regarding end-of-life care.

Physicians providing home care also experienced positivity such as feeling the warm atmosphere during end-of-life care and appreciation and respect for the deceased. This may have something to do with the culture of end-of-life care in Japan. In Japanese culture, the ritual care of the dead, like that seen in the Oscar-winning movie "Okuribito" ("Departures"), is valued,31 and such a cultural aspect also seemed to influence the family physicians’ behaviors in end-of-life care.32 The ritual care and preparation of a body are carefully crafted in the ceremonial form such as that of a traditional tea ceremony. In the present study, some physicians mentioned that such a ritualistic and aesthetic manner toward the deceased was important in their end-of-life care, and it seemed to have naturally led to emotional care for the family. In Japan, postmortem care of the dead in hospitals is mainly performed by nurses and rarely by doctors as part of their duties.33 The protocol and etiquette for touching the body after death varies greatly from culture to culture.34 It is greatly influenced by each culture’s view of life and death and religious beliefs.34,35 This is one of the novelties of this study because there is almost no literature in the world that describes the meaning of doctors touching the body after the death of a patient. In the previous study, physician trainees in the United States who felt various distress developed detached and dehumanizing attitudes toward end-of-life patients as a coping mechanism,12 which contrasts with the fact that the young doctors in the current study seemed to feel some positive feelings and developed positive attitudes during end-of-life care.

Although our study provides some interesting insights into end-of-life care, it may have some limitations: the study analyzed a limited number of Japanese family physicians, and the subjects were limited to young family physicians. Thus, the present findings might not be transferrable to more experienced family physicians or experts in other fields. In addition, due to the relatively small sample size, the data did not reach theoretical saturation. In the future, a nationwide study with a larger number of participants is desirable.
to clarify the emotional challenges of physicians involved in home-based end-of-life care.

It is hoped that this study will lead to the inclusion of aspects such as how to deal with one's own emotional aspects in the training of physicians in end-of-life care. Further research is expected to elucidate whether the diversity of emotional aspects of physicians in home-based end-of-life care observed in this study will be recognized worldwide.

5 | CONCLUSION

Family physicians experience various emotions and struggles while providing end-of-life home care. These issues derived from uncertainties at the end of life, their own emotions and roles, communicating with the family, and so on. However, physicians providing home care also experienced positive emotions such as a warm atmosphere during end-of-life care and appreciation and respect for the deceased.

AUTHOR CONTRIBUTIONS

DS and AO interviewed participants, and were major contributors in analyzing the text data and writing the manuscript. DS, AO, and ST discussed the qualitative analysis, and ST assisted in writing the manuscript. All authors read and approved the final manuscript.

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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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SUPPORTING INFORMATION
Additional supporting information can be found online in the Supporting Information section at the end of this article.