

Using Narrative Approach for Anticipatory Grief Among Family Caregivers at Home

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Abstract

Family caregivers of patients with terminal-stage cancer have numerous roles as caregivers, which can influence their anticipatory grief. The purpose of this study was to clarify how talking to family caregivers of patients with terminal illness using the narrative approach can influence such caregivers' process of anticipatory grief. We conducted the narrative approach as an intervention with two family caregivers several times and qualitatively analyzed their narratives. The results indicated that these family caregivers had two primary roles—family member and caregiver—and that family caregivers felt trapped in their caregiver role. The narrative approach helped them transition into the role needed for coping with the loss.

Keywords

bereavement / grief, caregivers / caregiving, end-of-life issues, narrative inquiry; nursing

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Background

In recent years, the length of hospital stay for cancer patients at the terminal stage has shortened in Japan. This has coincided with an accelerating transition to home care. Although the proportion of patients receiving end-of-life care at home is not yet high, it is expected to increase with the recent development of a system of community medical/nursing care services that promote cancer control programs. This increase in end-of-life care at home will doubtlessly increase the rate of family caregivers. Thus, it is becoming increasingly important to develop methods of supporting them. The care provided by the family caregivers of cancer patients at the terminal stage—namely, the disease stage where the prognosis is 6 months or less and medical treatment aimed at recovery is no longer possible—differs from nursing care; aside from merely providing personal care, family caregivers must constantly observe the patient in place of a nurse. Therefore, care provided by family caregivers does not only refer to taking care of patients' personal belongings, but also to observing the patient's life.

Family caregivers are often aware of their own significance and role in care, which can become a source of internal support. However, they may begin to resent family members who do not show an interest in helping with such care (Ishi, Miyashita, Sato, & Ozawa, 2011). Care is often handled by a single main family caregiver, which often leaves that caregiver with no room to grieve or prepare for the death of their

immediate family member. This form of preparation is known as “anticipatory grief.” In other words, anticipatory grief is the grief reaction that occurs in anticipation of an impending loss (Casarett, Kutner, Abrahm, & Panel End-of-Life Care Consensus, 2001). However, it can be difficult for individuals to face anticipatory grief on their own. As such, effective interventions enabling these family caregivers to face and confront their emotions during home care may be necessary.

In this study, therefore, we conducted a narrative approach, focusing on the actual situation of care provided by family caregivers as well as their emotions related to performing such care. The narrative approach used herein referred to the technique whereby a researcher provides feedback on what family caregivers talk about, to help those caregivers objectively recognize their own emotions. This, in turn, can help caregivers better express and manage their “ever-swaying” emotions during the cancer patient's terminal stage. We considered the narrative approach appropriate for promoting the anticipatory grief of family caregivers in Japan.

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Literature Review

Anticipatory grief. The families of cancer patients are exposed to considerable physical, mental, and social stress. It is recognized that the opportunity for family members to process the idea that the patient will die and thereby experience anticipatory grief is very important for them to progress through the grieving process, both before and after bereavement (Lindemann, 1944; Parkes, 1976). Anticipatory grief is defined as a normal response or experience resulting from the anticipation of loss. Overall, anticipatory grief appears to be an essential part of the natural process of coping with loss; however, interestingly, intervention appears to often be necessary to help individuals experience anticipatory grief (Costello, 1999; Worden, 2009). Indeed, according to Burke et al. (2015), a “constellation of factors” can complicate the end-of-life mourning process for family members, suggesting that early assessment and treatment of grief-related problems—through a focus on anticipatory grief—is necessary.

Anticipatory grief is believed to have various aspects and occur in several stages. Specifically, the process of anticipatory grief can be said to follow the general process of experiencing shock about the upcoming loss, denying the reality of the loss, and eventual acceptance (Duke, 1998; Kübler-Ross, 2001; Okawa et al., 2001). In other words, anticipatory grief appears to change over time. However, anticipatory grief should be viewed as a mental process for adapting or dealing with the patient’s illness or death, and, as such, is not merely a reaction to the prospect of the patient’s death arising over time (Rando, 2000). Notably, a recent systematic review indicated that there was no protective function of grief symptoms against bereavement outcomes during caregiving (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). However, anticipating death can make caregivers grow more aware of the patients and their own mortality; often, they experience a sense of being “static in time” and feel that it is impossible to plan for the future (Olson, 2014), which can lead to possible maladaptive responses to bereavement (Levy, 1991). Indeed, anticipatory grief has been found to be significantly but weakly correlated with postdeath grief—specifically, it is associated with higher intensity of anger, loss of emotional control, and atypical grief responses (Fleming, 1998; Liu & Lai, 2006). As such, there appears to be some controversy regarding the significance of anticipatory grief. According to Coelho and Barbosa (2016), “[anticipatory grief] is (a) multidimensional and dynamic process. The heuristic value of this concept concerns its clinical implications, considering that a better understanding of this phenomenon will promote a more sensitive intervention” (Conclusions section, para. 1). Despite this, there currently are no clear interventions for helping family caregivers with anticipatory grief.

Although we believe that there is no need to force individuals to experience anticipatory grief, we do believe that the development of an approach to promoting it would be necessary for some individuals. Indeed, anticipatory grief

can be beneficial for individuals when dealt with correctly. While evoking anticipatory grief may be unreasonable, helping individuals notice their own anticipatory grief through intervention can help them face it properly.

Previous studies on grief mainly comprised interviews and questionnaire surveys conducted after family caregivers had lost a loved one. There are no studies that have clarified how anticipatory grief interventions delivered by visiting nurses—namely, while the patient with terminal illness is still receiving nursing care—influence caregivers’ postmortem feelings. In this study, therefore, we aimed to clarify how the anticipatory grief of family caregivers is reframed after an intervention performed during home care.

Narrative approach. Lazarus (2004) described the narrative approach as a method for evaluating and promoting subjects’ reframing of emotional experiences, with a focus on the process of this reframing. Through this process, one can explore an individual’s emotions and delve into the essence of the topic of interest. The narrative approach involves encouraging talk to restructure a subject’s emotions and is most effective when the subject’s experiences are rather recent—that way, they can be reproduced more realistically, and the narratives can better reflect human nature. The narrative approach has been effectively used for patients with chronic pain, who were able to develop new stories applicable to their current lives via talking (Dysvik, Natvig, & Furnes, 2013). Similarly, the narrative approach can be effective for helping individuals perceive emotions that they cannot easily accept (Morris, Simpson, Sampson, & Beesley, 2015). Talking also helps individuals distance themselves from negative emotions or situations and transition into more positive stories, such as by developing hope. Therefore, family caregivers in a solitary environment may be able to find hope through talking (Williams et al., 2013). Although the narrative approach cannot change the fact of a loss, it can help to reframe the significance or “story” related to that loss. Therefore, the use of a narrative approach at regular visits by a nurse may be able to help family caregivers engage in anticipatory grief and thereby develop a new story.

The narrative approach has been utilized in a variety of fields, including sociology, psychology, medical science, and cultural anthropology. Its theoretical basis in the present study lies in social constructionism (Sheila & Kenneth, 1992/2004). Specifically, the approach was used to elucidate and reframe the structure of an individual’s reality, with the narrative being an indicator of that reality (Sheila & Kenneth, 1992/2004).

Purpose

The purpose of this study was to explore and clarify how talking to family caregivers of patients with end-of-life illness using the narrative approach influences the process of anticipatory grief. The process of caring for ill and dying

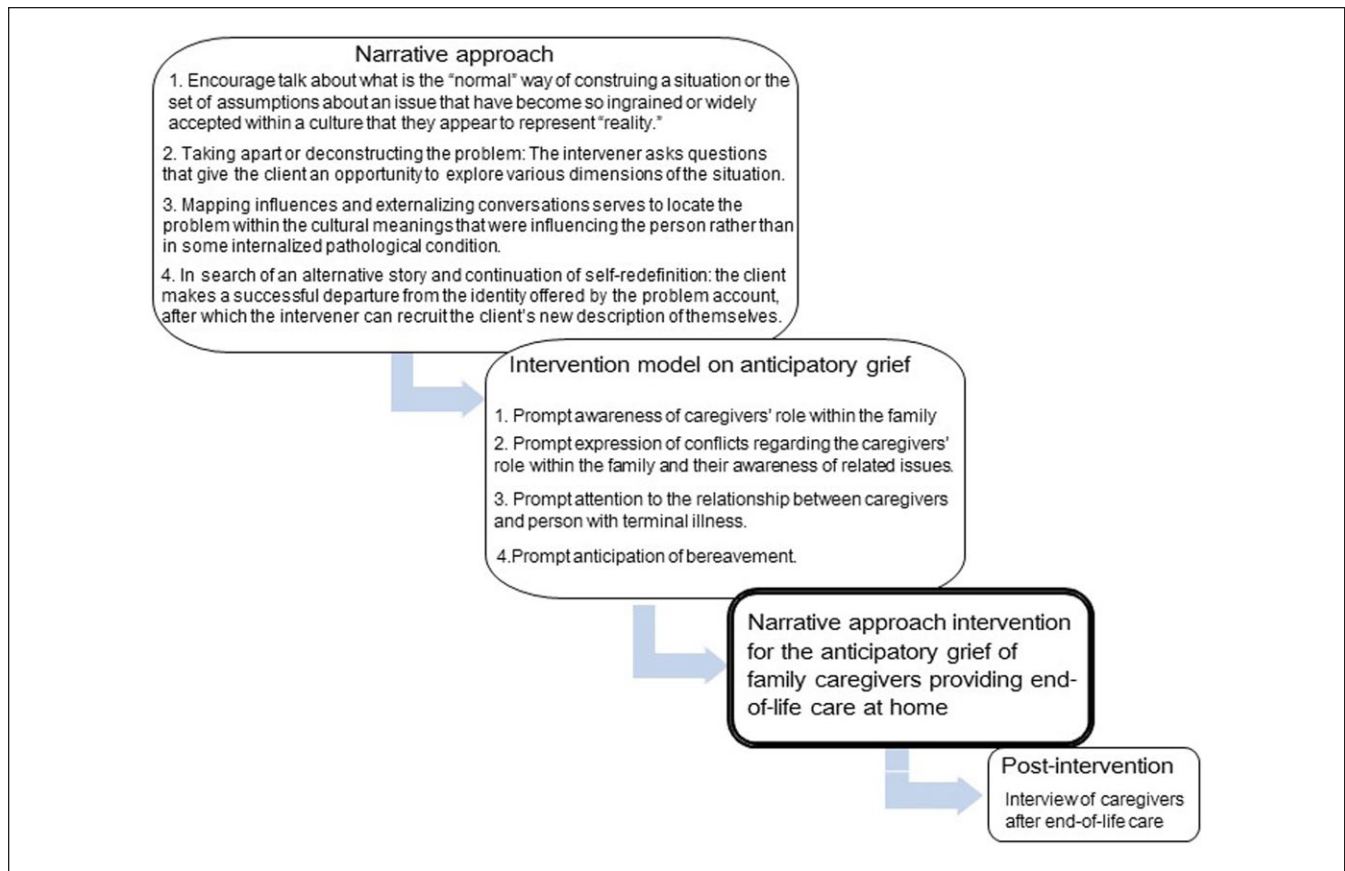


Figure 1. Flowchart of this study.

family members is nearly ubiquitous across the world, as is the psychological burden of facing end-of-life care. It is believed, then, that interventions for reframing anticipatory grief may be of use worldwide.

Method

Study Design

This was a qualitative intervention study targeting family caregivers (see Figure 1). The intervention model of anticipatory grief was created using the narrative approach and a social constructionist perspective.

Intervention

Narrative approach. Although the narrative approach has been widely utilized, there is no standardized method. Narratives are always developed using the mutual relationship between subject and intervener; as such, the intervener must always attempt to expand the field of conversation to allow them both to explore each other, and should adopt an attitude of “intentional ignorance” at all times (Fukura, 2015). With this in mind, a framework was created with reference to the theoretical foundations of the narrative approach proposed

by Michael White, David Epston, and others. The framework is as follows.

1. Encourage talk about what is the “normal” way of construing a situation or the set of assumptions about an issue that have become so ingrained or widely accepted within a culture that they appear to represent “reality.”
2. Taking apart or deconstructing the problem: The intervener asks questions that give the client an opportunity to explore various dimensions of the situation.
3. Mapping influences and externalizing conversations serves to locate the problem within the cultural meanings influencing the person rather than in some internalized pathological condition.
4. In search of an alternative story and continuation of self-redefinition: The client makes a successful departure from the identity offered by the problem account, after which the intervener can recruit the client’s new description of themselves.

Development of the intervention model on anticipatory grief. Families who care for patients in their terminal stage of illness at home are likely to experience high stress on a nearly

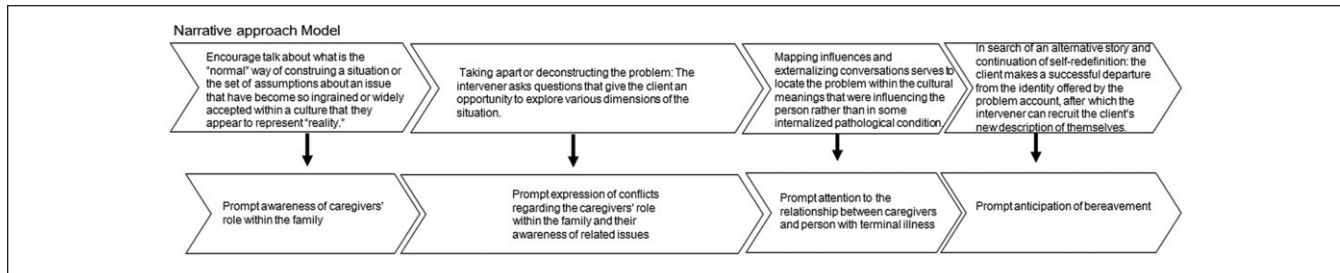


Figure 2. Intervention model of anticipatory grief.

24-hour basis. As the patient's condition deteriorates, the family is forced to concentrate more on care; in this way, the duties of the family caregiver increase almost daily. Furthermore, such care centers on the family and is provided within a closed environment disconnected from the outside world. Visiting nurses can provide mental support to family caregivers, specifically by pointing out how to take responsibility as a caregiver, offering information about certain care methods and points of observation, and listening to caregivers' concerns. They can also suggest various societal resources that caregivers might utilize (Figure 2).

In attempting to fulfill their caregiver roles in this way, family caregivers might be inhibited from grieving as family members. To help family caregivers realize their role as family members through anticipatory grief, and that this role is part of their role as family caregivers, we devised an intervention model from the results of a preinterview with family caregivers and past literature (Kosako, 2012; Moriyama, 2002; Nagato & Sakamoto, 2014; Suzuki, 2003; Watanabe, 2003; Yanagihara, 2008), which we then used as a framework for delivering the narrative approach. The specific goals of the intervention were as follows:

1. Prompt awareness of caregivers' role within the family.
2. Prompt expression of conflicts regarding the caregivers' role within the family and their awareness of related issues.
3. Prompt attention to the relationship between caregivers and person with terminal illness.
4. Prompt anticipation of bereavement.

Participants

Participants included the main family caregivers (hereinafter, "family caregivers") providing end-of-life care at home for cancer patients (hereinafter, "patients") with an estimated life expectancy of 6 months according to their primary physicians. All patients were also utilizing a visiting nurse service. Family caregivers comprised five children (three daughters, one son, and one daughter-in-law) and five spouses (four wives and one husband). All participants considered themselves caregivers and were able to talk about the treatment situation.

Procedure

Family caregivers were referred to us by the visiting nurse stations, and were only visited after obtaining their consent. The interventions began after giving caregivers a written or verbal explanation of the study purpose and obtaining their signature on a consent form. Each interview lasted for 60 minutes or less and multiple interviews were conducted for each caregiver. The intervention was carried out by one researcher in order to standardize the intervention.

Data Collection

Interventions were performed continuously until the patient's death using the intervention model prepared beforehand. After that, another intervention was conducted. All of the exchanges were audio recorded during each intervention session using an IC recorder after obtaining consent from the caregivers. These exchanges were then used in the subsequent analysis. Supplemental data were kept in a field notebook, wherein the interviewer's observations of family caregivers' appearance and responses were recorded, as well as the interviewer's thoughts on the situation during each intervention session.

The data obtained from each intervention session were analyzed soon after the session finished, and feedback was provided to the caregivers after this analysis. Then, interventions were repeated.

Analysis Method

Narratives are constructed from the bidirectional interactions between the interviewer and client. Therefore, to clarify how clients' narratives are reframed, it is necessary to note how the researchers intervened. This helps to provide objectivity about the intervention contents by analyzing how researchers performed the intervention. In the present study, the intervention and the intervener's perspective are the same; as such, it would be important to analyze the researcher's narrative to perceive the intervention in an objective way.

Extract individualities in the narrative. The analysis process was as follows. First, the data of all recorded interventions were

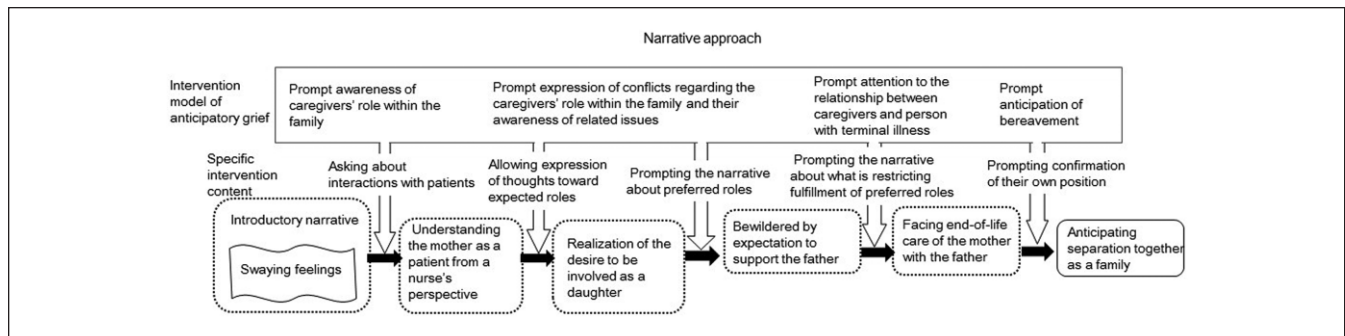


Figure 3. Reframe in anticipatory grief of Caregiver A.

transcribed verbatim. Second, we carefully read the contents of each conversation while considering the overall narrative and the interactions between researcher and caregiver. Third, we identified and extracted the parts of the conversations showing clear changes in meaning or emotional transitions with regard to the narrative, such as emotions expressed in response to questions or aspects of participants' awareness. Fourth, we consolidated the extracted content into single sentences to clarify the meaning of such content (creating, in effect, a "substory"). Fifth, we read each of the substories and noted any similarities. Finally, substories with similar content were combined and summarized to form whole "stories."

Extracting commonalities in the narratives. The stories extracted from the caregivers' intervention were combined and summarized according to their common meanings to provide an understanding of the overall process of reframing. The results of this analysis were "themes."

Trustworthiness. A researcher who was skilled in qualitative research and experts in qualitative research confirmed the credibility of the analysis results after each intervention. Additionally, qualitative researchers not involved in the present study were called in and asked to help in confirming the validity of the overall analysis results. Finally, we performed member checking, wherein each participant confirmed the intervention results.

Ethical Consideration

This study was conducted in compliance with the "Ethical Guidelines for Clinical Studies" of the Ministry of Health, Labour and Welfare as well as the "Ethical Guidelines for Nursing Research" by the Japanese Nursing Association. Before asking for their consent, subjects were informed of the nature of study participation, including that it was entirely voluntary, that they could stop at any point, that the collected data would be used for research purposes only, and that their confidentiality would be strictly maintained. We also obtained approval from the institutional review board of our affiliated university.

Research Findings

Case Overview

We describe only two of the 11 family caregivers who were referred by five visiting nurse stations in the following analysis. We excluded the other nine because the patient was hospitalized during the study period or had died before we could begin the intervention.

The patients under the care of the two participating caregivers were diagnosed with terminal cancer and had life expectancies of less than 6 months. Both subjects were main caregivers providing nursing care almost exclusively. The patient in Case A had been informed of her disease, while the patient in Case B had not been informed of his disease or life expectancy. In Case A, the caregiver was the patient's daughter, who was a nurse (Family Caregiver A); in Case B, the caregiver was the patient's wife, who was a cancer survivor (Family Caregiver B). Both family caregivers lived with other family members in addition to the patient. Family Caregiver A was in her 20s and Family caregiver B in her 50s. In total, we performed six and three intervention sessions for these caregivers, respectively.

Reframes in Anticipatory Grief as a Result of Intervention

In the following sections, the intervention stories synthesized from the data are enclosed with square brackets (i.e., []).

Reframes in the anticipatory grief for Family Caregiver A

Understanding the mother as a patient from the viewpoint of a nurse. When we initially questioned Family Caregiver A about the patient's illness, she spoke objectively about the physical condition of the patient from the viewpoint of a nurse. As part of the intervention to help her realize her role within the family, we asked about the [advantages and disadvantages of being a medical professional]. She began to talk about how she felt trapped in the caregiver role, stating that it was not possible for her to express her emotions as a daughter because she considered her mother a patient (see Figure 3 and Table 1).

Table 1. Common Reframes of Anticipatory Grief for Family Caregiver A.

Common Themes of Anticipatory Grief in Caregivers A and B	Reframes of Anticipatory Grief of Caregiver A	
	Story	Substory
Talking about their obsession with their expected role in the family	Understanding the mother as a patient from a own job's perspective	I want to be involved as a daughter, but the family expects me to have the role of health care worker I was an emotional yo-yo due to my mother's health condition
Responding to expectations within the family in a way that does not fit with the present self	Realization of the desire to be involved as a daughter Bewildered by expectation to support the father	I talked about having insufficient emotional expression—in other words, since I had no outlet for my feelings, I kept them to myself My dilemma and anger, which I was previously not aware of, was illuminating: I hoped but was not able to share my feelings of grief with my father, who was avoiding facing the death of my mother I had a desire to not acknowledge that my mother's death was approaching while still experiencing a general feeling of anticipation of future loss I attempted to have my father face reality, because I hoped to obtain his help in the nursing care of my mother In relation to my caregiver role within the family, I felt a sense of desolation arising from my expected role as a nurse and not being able to be involved as a member of the same family
Facing the patient departing for death as a family member	Facing the end-of-life care of the mother with the father	I mentioned that it became painful to talk when I began to understand my shifting emotions, but that talking still helped me organize my thoughts I feared losing my mother, and this fear derived from my identity as a daughter rather than my identity as a nurse I expressed how being able to prepare for the end-of-life care of my mother had helped relieve me of the burden of supporting my father's anticipatory grief, because this preparation, which we performed together, brought him some closure
Grieving in anticipation of loss from the viewpoint of a family member	Anticipating separation together as a family	I was able to organize my thoughts so that I could understand my father's thoughts and better provide end-of-life care to my mother alongside him I talked about my desire to do everything I could in lockstep with other family members until the end, rather than performing the caregiver role on my own; I felt that I had to soak myself in sorrow alongside my father

Researcher (R): It seems beneficial because you are a medical professional, but on the other hand, it means that you will be able to understand the situation when the results are not good, to some extent.

Family Caregiver A (A): That's right. I also need to work as a bridge and give an explanation to my family on what was not so good (about the treatment). I am accountable in that sense.

R: Would it be like everyone in the family relies on you—do you feel responsible?

A: It is kind of tough (she tears up) and painful to me because I can foresee what will happen. Also, when I need to stay calm but get emotional, I am sure that my family will feel shaken. So, I tell myself that I have to be very strong.

R: You might not have thought that way if you were not a medical professional. In this sense, you are different from other family members.

Realization of the desire to be involved as a daughter. Family Caregiver A experienced emotional conflict between her caregiver role and her thoughts as a daughter. Therefore, Family Caregiver A's [swaying thoughts were specifically drawn out]. Family Caregiver A talked about having insufficient emotional expression—in other words, she had no outlet for her feelings, instead keeping them to herself.

Furthermore, we asked about [specific details on nursing care that had been implemented successfully by Family Caregiver A because she is a medical professional] as well as [how she responded to her father], who had difficulty facing

reality. In the conversation, she reported how she was unable to express her emotions because of a sense of feeling trapped in her caregiver role, and how she was desperately trying to make her father experience anticipatory grief. In this way, Family Caregiver A's dilemma and anger, which she was previously not aware of, was illuminated: She hoped but was not able to share her feelings of grief with her father, who was escaping from facing the death of her mother.

R: Ms. A, you mentioned last time about your desire to provide nursing care as a daughter, not as a medical professional, yet your family sometimes relies on you. Could you explain about more specific situations?

A: I don't mind answering questions like, "What happens if we give a transfusion now?" I don't like being responsible for making the decision on giving a transfusion or not, or on going to the hospital or not. I am not sure about being in charge of . . .

R: You mean specific decision-making?

A: Yes.

R: I assume the primary physician presents specific options. Are you supposed to make a decision, not your father?

A: Yes, I am ultimately asked about which is better.

R: Are you asked for your opinions as a medical professional?

A: That's right. My father is normally inclined to agree with the doctors. He tends to leave everything to a doctor, and does not interfere much. He just gives everything over.

Bewildered by expectations to support the father. When Family Caregiver A was encouraged to [perceive how she understood the situation of her terminally ill mother] as she watched her mother's condition deteriorate, she talked about her desire to not acknowledge that her mother's death was approaching while still experiencing a general feeling of anticipation of future loss. She also became aware of the fact that she had begun to explain the reality of the situation to her father, who lived with her, so that her father could not escape from it. Her attempt to have her father face reality was partially in hopes of obtaining his aid in the nursing care of her mother. In relation to her caregiver role within the family, she spoke of the feeling of desolation arising from her expected role as a nurse and not being able to be involved as a member of the same family. She eventually realized that she had no ability to care for her father because she herself was unable to acknowledge the impending loss of her mother. In other words, she came to realize that the issue of her caregiver role within the family was separate from the issue of her swaying thoughts.

A: I cannot imagine things like my mother's life lasting until winter . . . (But) I cannot help thinking about whether or not she

will be healthy until then. So, I don't want to think too much about the future.

R: If even you feel this way, would your father feel it much more so?

A: I assume so. Maybe that's why he asks about how much longer (it will be). Probably he wants to convince himself that she will be OK until then, to get some kind of confirmation.

R: Not for preparation?

A: I think he asks questions to get a sense of reassurance. However, I am not able to answer that question (about how long it will be).

R: No one knows that. Would you just keep it vague?

A: Rather than keeping it vague, we would just talk about whether today is good (or whether) everything is good. That's also my father's interpretation, I think. He says that he might also have a traffic accident tomorrow. It's better if we can think about the future with hope, but I am unable to think that way.

Facing end-of-life care of the mother with the father. Family Caregiver A mentioned that it became painful to talk when she began to understand her shifting emotions, but that talking still helped her organize her thoughts. She came to realize that she was able to view her thoughts objectively and that talking itself had become a kind of anticipatory grief. When [her feelings were drawn out with a direct question about her desire to stay with her mother to prepare for the predicted time of death], she realized that she feared losing her mother, and that this fear derived from her identity as a daughter rather than her identity as a nurse. She went on to express how being able to prepare for the end-of-life care of her mother had helped relieve her of the burden of supporting her father's anticipatory grief, because this preparation, which they performed together, brought him some closure. Through repeated conversations on this topic, it gradually became clearer how she had to reorient herself toward the impending loss.

A: (My father) does not look as upset as he used to before, and I feel a little relieved myself. I don't feel pressed to convince him. It's easy for me when he is hanging tight.

R: You would say that you had to do something about your father, but you don't feel this way now?

A: It probably changed when she was hospitalized. I was also at the hospital when she was there. I assume he thought about many things at home by himself. I am not sure what he was thinking, though.

Anticipating separation together as a family. In this last stage, the intervention was to [to help Family Caregiver A talk about

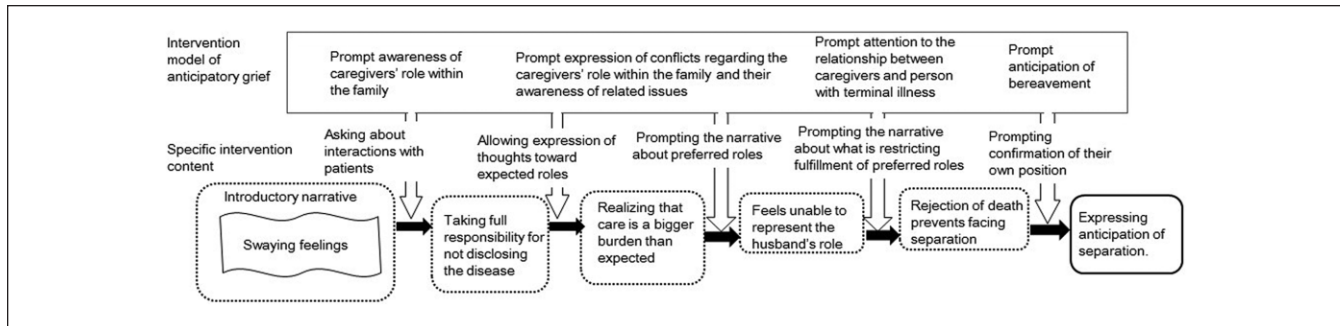


Figure 4. Reframe in anticipatory grief of Caregiver B.

reframing her father's sentiments about her mother's difficult situation]. Through this intervention, Family Caregiver A was able to organize her thoughts so that she could understand her father's thoughts and better provide end-of-life care to her mother alongside him. She also talked about her desire to do everything she could in lockstep with other family members until the end, rather than performing the family caregiver role on her own; she felt that she had to soak herself in sorrow in alongside her father. As described above, she reported reframes in how she approached her father, which lead to an ability to express her own emotions and grieve.

A: He probably didn't like the idea that if he didn't go on his business trip, he was acknowledging that something would happen during that time. He might have thought it could be the end.

R: Did he let go of such an idea?

A: Yes, he said he let go of it.

R: Did he say it himself?

A: I asked him, because he looked very worried. He wanted to take off time from work but didn't want to acknowledge it. He looked upset about something, at that time. Then he said that it didn't matter, because my mother was OK.

R: Was it the first time he talked about these things directly?

A: Yes, it was the first time.

R: Did you feel you clearly understood your father's thoughts?

A: Yes, it is not exactly that I was relieved, but I understood why he had asked how long. He might have had conflicting thoughts that he didn't want to acknowledge yet had to prepare himself mentally (for, anyways). I think at least he reconfirmed that my mother was a priority.

Reframes in the anticipatory grief of Family Caregiver B

Taking full responsibility for not disclosing the disease. Family Caregiver B's husband, the patient, was not informed

of the nature of his disease. Indeed, the disclosure was made to Family Caregiver B herself only several months prior to the first intervention. Family Caregiver B initially talked about changes in her husband's physical condition and her feelings of anxiety in the beginning. The intervener [asked about detailed changes in the patient's condition that she had observed as a main caregiver], and she reported a strong resolution to fulfill the caregiver role and provide end-of-life care in all circumstances, despite her feelings of insecurity. Furthermore, she persuaded herself to not rely on anyone (see Figure 4 and Table 2).

B: I was very worried at the time of hospital discharge. I didn't know what to do. The word "hospice" also sounded like someone else's problem. So, I was totally anxious.

(Pause)

B: I assume (that he thinks) he does not have cancer. He is probably feeling this is taking a long time, but would never think that he had come this far.

R: What do you anticipate will happen in the future? What do you think about not disclosing in this situation?

B: Yes, I agree.

R: I think you are the easiest person for him to talk with.

B: He never tells me this. He only says he will get better. Another thing is that he started to have severe back pain last week, something that he hadn't experienced before. Why does that happen at such an important time as this? [. . .] I think I started to get weary too. You cannot care for someone unless you are healthy yourself. That must be it.

Realizing that care is a bigger burden than expected. The intervener expressed empathy repeatedly to Family Caregiver B regarding her complaints of having to provide care despite the fact that she had already reached her physical limits. Furthermore, the intervener conducted an intervention by [confirming her swaying thoughts and prompting her to talk]. In this way, Family Caregiver B came to realize

Table 2. Common Reframes of Anticipatory Grief for Family Caregiver B.

Common Themes of Anticipatory Grief For Caregivers A and B	Reframes of Anticipatory Grief of Caregiver B	
	Story	Substory
Talking about their obsession with their expected role in the family	Taking full responsibility for not disclosing the disease	I provided end-of-life care in all circumstances, despite my feelings of insecurity I persuaded myself to not rely on anyone
Responding to expectations within the family in a way that does not fit with the present self	Realizing that care is a bigger burden than expected	I came to realize my responsibility as the only caregiver for my husband and the limitations of providing nursing care I was able to clarify the conflict between not being able to accept death while attempting to make arrangements for bereavement as the main caregiver
	Feeling unable to represent the husband's role	I realize the frustration and regret of not being able to resolve my husband's issues for him I mentioned that my husband could not die yet because he still had a role to fulfill
Facing the patient departing for death as a family member	Rejection of death prevents facing separation	I had a sense of panic despite believing that I was prepared for end-of-life care I had hope about my husband's life expectancy because I was a cancer survivor I had no idea what I would do after my husband's death
Grieving in anticipation of loss from the viewpoint of a family member	Expressing anticipation of separation	I became able to honestly express my feelings I found that it was becoming easier to anticipate separation from my husband

her responsibility as the only caregiver for her husband as well as the limitations of providing nursing care. At the same time, she was able to clarify the conflict between not being able to accept death while attempting to make arrangements for bereavement as the main caregiver.

B: Rather than changes, it is more like I need to constantly watch over him and am unable to leave the house. I also mentioned to our daughter that it might be getting close. . . . She would check out mortuaries on the PC and talk about how to perform the procedure (for funeral arrangements), but we won't know about that until just before his death.

R: Yes, that's true.

B: I am making that kind of preparation behind his back. In that sense, I might be already prepared, although I won't know when it really happens. . . . I have no choice but to take good care of this. Anyway, what's different from last week is that I cannot leave the house.

R: Is that so? It is true that you won't know how Mr. W will change in the coming week.

Feels unable to represent the husband's role. The intervener conducted an intervention for Family Caregiver B to direct her to face the family issues surrounding the husband by [advocating for the feelings of the patient during treatment]. This helped her realize the frustration and regret of not being able to resolve her husband's issues for him or fulfill her husband's role within the family. However, when the

intervener intervened [to substantiate the subject's thoughts about resolving family issues and to encourage expression of these thoughts to her husband], she mentioned that her husband could not die yet because he still had a role to fulfill. She expressed her belief that her husband needed to resolve yet unresolved family problems. This helped clarify her conflicted thoughts, which swayed between family problems that could not be handled by a daughter-in-law and thoughts about her husband, who was departing for death.

B: I become anxious thinking about the future even when I am asleep. What should I do? My husband is the firstborn son. His 92-year-old mother is still doing well. He is genuinely firstborn. Everyone in the household relies on the firstborn son, and everything important is left to him. If he dies, everyone will be troubled, and I start thinking about what to do at midnight.

R: And your husband thinks he will get better.

B: There may be things he has to do around this time.

Rejection of death prevents facing separation. Family Caregiver B became confused about her husband's rapidly deteriorating condition, so the intervener [communicated this confused state to her]. When the [patient's thoughts were expressed for her], she reported a sense of panic despite believing that she prepared for end-of-life care. [The fact that Family Caregiver B was unable to face reality was then provided as feedback]. Even as her husband's ability to respond to questions became increasingly impaired, Family Caregiver B mentioned that she

Table 3. Common Reframe in Anticipatory Grief for Caregivers A and B.

Common Reframe in Anticipatory Grief for Caregivers A and B	Reframe in Anticipatory Grief of Caregiver A	Reframe in Anticipatory Grief of Caregiver B
Introductory narrative	Swaying feelings	Swaying feelings
Talking about that they were trapped with their expected role in the family	Understanding the mother as a patient from a nurse's perspective	Taking full responsibility for not disclosing the disease
Responding to expectations within the family does not fit with the present self	Realization of the desire to be involved as a daughter	Realizing that care is a bigger burden than expected
Facing the patient departing for death as a family member	Bewildered by expectation to support the father	Feels unable to represent the husband's role
Grieving in anticipation of loss from the viewpoint of a family member	Facing end-of-life care of the mother with the father	Rejection of death prevents facing separation
	Anticipating separation together as a family	Expressing anticipation of separation

had hope about her husband's life expectancy because she was a cancer survivor. When [specific details on family issues to be resolved were asked about], she came to realize that she had no idea what she would do after her husband's death. Based on this, she confirmed that she would face her husband as his wife in the present, and would assume her husband's role as head of the household.

R: Is it different now, compared with your case?

B: I could not help telling him, "What are you doing! This is not even an illness! Get better soon." Then, when we left the hospital the other day, he murmured, "You said that I am not ill."

R: Mr. W might have prepared himself to some extent.

B: Probably, yes. He is the one who is feminine and vulnerable.

R: Were you upset yesterday, though?

B: Yes. I don't know what to say but when I first heard that he would only live for 2 months, I felt sad thinking that he would be gone from my sight. I wondered where he was going, though he was always with me. I will have no one to talk to. Now, I see him when I look back. It might have been yesterday, "but I said 'when the three of us were together. What should we do if he is gone next Sunday? It will be quiet.'"

Expressing anticipation of separation. Family Caregiver B [was asked about whether she was able to understand death as realistic] when talking about her husband's deteriorating condition. Through this, she became able to honestly express her feelings, describing that while she could give up, it was becoming easier to anticipate separation from her husband.

B: He might say ahhhh or uhhhh when I talk to him. I wouldn't know what he said.

R: You can talk to him more because he can hear until the end.

B: Oh, is that right? I said very severe things (laughs).

R: I think he heard them.

B: My daughter gets mad at me too, because I say terrible things!

R: I understand. Mr. W is listening to reminiscences, so please make him feel good to hear these happy memories.

B: Okay. I understand now.

Progress after end-of-life care. The intervener conducted an interview 6 months after providing end-of-life care, wherein the caregivers were asked about their feelings at present, during the care, and during the intervention. Both Family Caregivers A and B expressed the benefits of talking as well as the benefits of objectively reviewing the details of that conversation.

The benefits of talking for the caregivers included feeling relieved during the intervener's regular visits to conduct the intervention. Talking to someone who was at ease helped the caregivers feel temporarily freed from nursing care and from themselves, which in turn helped them organize their feelings. They were also able to objectively understand the situation and take action through the process of talking. By repeating the process of objective reflection on the details of the conversation, they clearly became able to understand their own actions and their family's thoughts.

Commonality in the Family Caregiver Narratives

The stories of Family Caregivers A and B were integrated and four themes were extracted (Table 3).

Talking about how they felt trapped within their expected role in the family. Family Caregiver A expressed how other family members had expected her to adopt the role of a nurse and view her mother as a patient, while Family Caregiver B

reported that others viewed her as exclusively having the role of main caregiver for her husband. This expectation made Family Caregiver B preoccupy herself with that role. In other words, both of them felt trapped in their caregiver role, a role that neither of them desired to fulfill.

Responding to expectations within the family does not fit with the present self. Family Caregiver A was aware of her desire to be involved in nursing care as a daughter in cooperation with her father, rather than fulfilling the role of nurse as expected by other family members. However, she was still conflicted by the thought that she had to provide nursing care and encourage her father's anticipatory grief. Family Caregiver B tried to force herself to fulfill her role as the exclusive caregiver, and at the same time recognized that it was a problem to act as her husband's substitute. This led her to feel conflicted by the idea that she was not sufficiently fulfilling either role.

Facing the patient departing for death as a family member. Both Family Caregivers A and B recognized that the roles expected of them by other family members were not their true roles, and began to prepare for the coming loss and end-of-life care while feeling exceedingly conflicted over this realization. However, Family Caregiver A came to be able to talk about her thoughts honestly from the standpoint of her role as a daughter, rather than as a nurse, and thereby was able to begin anticipating the loss of her mother with her father. Similarly, Family Caregiver B began to seek closure as a wife who would soon lose her husband, rather than as the main caregiver.

Grieving in anticipation of loss from the viewpoint of a family member. Ultimately, both caregivers were released from their feeling of being trapped in their caregiver role. Family Caregiver A came to anticipate and grieve for the loss of her mother as a daughter alongside her father; Family Caregiver B did the same while providing end-of-life care for her husband from the standpoint of a wife.

The above results show that the narrative approach was able to help the caregivers reframe their anticipatory grief. While caregivers initially felt trapped within the caregiver role expected of them by family members and felt inclined to fulfill this responsibility, the repeated interventions helped release them from feeling trapped and to express emotions as family members who anticipate loss and honestly face patients.

Intervener's Narrative

According to the intervention model of anticipatory grief, we also extracted common themes from the intervener's narrative.

Asking about interactions with patients. With a focus on the caregivers' perceived roles within the family, Family Caregiver A

was [asked about the advantages and disadvantages of being a medical professional], while Family Caregiver B was [asked about detailed changes in the patient's condition that she had observed as main caregiver]. These exchanges led the caregivers to begin talking about how they felt trapped in their roles within the family, wherein they reported experiencing emotions such as conflict and solitude. Prompting awareness of the caregivers' role within the family was achieved by our asking them about their interactions with patients.

Allowing expression of thoughts toward expected roles. [Swaying thoughts about their roles as caregivers and family members were specifically drawn out] to help caregivers express their struggles with their sense of obligation to fulfill familial roles, which had become clear to them while expressing their narratives. Furthermore, it helped them to express the loneliness of performing such roles. For Family Caregiver A, the intervener [asked about specific nursing care that can be provided because the family caregiver is actually a medical professional]. Furthermore, [Family Caregiver A's method of responding to the father was determined]; notably, the father appeared to be having difficulty in facing the reality of his wife's impending death. In addition, the intervener expressed empathy for Family Caregiver B, which helped prompt [their narrative while confirming the details of the caregivers' swaying thoughts between the roles of caregiver and family]. Thus, prompting expression of conflicts concerning the caregivers' role within the family and their awareness of related issues allowed for their expression of thoughts toward the expected roles.

Prompting the narrative about preferred roles. To elicit more of Family Caregiver A's narrative, [her words and actions directed at the father were drawn out to reconfirm her own position within the family]. This helped her realize that she was in a different position from her father, even though they were effectively in the same situation. For Family Caregiver B, [thoughts on behalf of the husband regarding family issues requiring resolution were crystallized and expression of these thoughts to her husband was encouraged]. In other words, the intervener urged Family Caregiver B to express her narrative of her role as a surrogate husband to help make her aware of these family issues and thus bring them to the surface.

Prompting the narrative about what is restricting fulfillment of preferred roles. As the narrative progressed, caregivers swayed between adhering to their roles expected of them by their family and acting on their own. When such swaying occurred, the intervener gave feedback on their narrative as accurately as possible and gave voice to patients' possible thoughts. For Family Caregiver A, [the intervention was conducted in such a way that Family Caregiver A could grasp her father's perspective by confirming how he understood her mother's deteriorating condition]. For Family

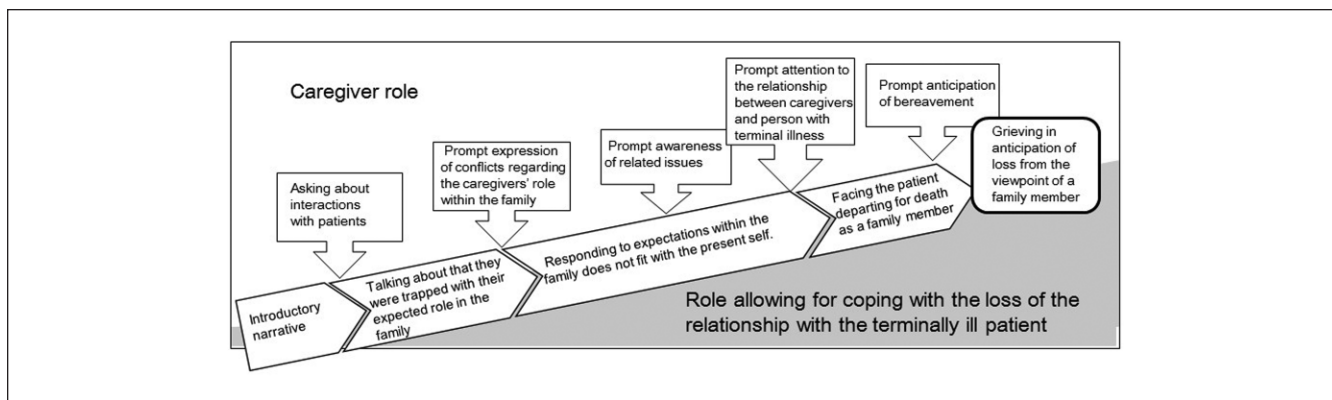


Figure 5. Common reframe in anticipatory grief for Caregivers A and B.

Caregiver B, [her confused state about her husband's rapidly deteriorating condition was communicated and her husband's thoughts were voiced]. This led to her being more aware of her role as a wife.

Overall, prompting caregivers' attention to their relationship with the patient helped them to objectively recognize their own thoughts. This in turn led to our prompting them to consider the narrative on what was restricting them from fulfilling their preferred roles. As a result, the caregivers were able to determine for themselves whether the family role was truly what they wanted.

Prompting confirmation of their own positions. For Family Caregiver A, under the circumstances of her mother's approaching death, the intervener prompted [confirmation of her cooperation with her father and other family members and her thoughts on each one's role in the situation]. Furthermore, the intervener prompted [her to relate what constituted a "grave" in her reality when the topic came up in a conversation on the deteriorating condition of her mother]. This brought up emotions about her role as a family member in preparing for a loss rather than as a caregiver, which in turn helped promote feelings of anticipatory grief. In other words, prompting anticipation of bereavement helped them to confirm their own positions.

Discussion

This study discussed the process of changing anticipatory grief as part of a narrative approach and determined how familial roles influence anticipatory grief among family caregivers providing end-of-life care at home.

Transition Between Caregivers' Roles

The reframes in anticipatory grief identified in this study manifested as shifts from caregivers' adherence to the family caregiver role to their adherence to a role that helped them cope with the loss of the terminally ill patient. Without this

shift, family caregivers could not otherwise adopt the necessary role to cope with the loss (in the case of this study, the role of daughter or wife), as adhering to the caregiver role forced them to suppress their emotions. By being released from the caregiver role, they could better express their emotions and therefore cope with the loss (Figure 5).

From the beginning of the intervention, family caregivers talked about feeling controlled by their caregiver responsibilities. Given that individuals' obligations and responsibilities are often determined by their specific relationships with others, we suspect that the caregivers' responsibilities were created by their relationships with their family members and the patient. These responsibilities included provision of daily nursing care in a timely fashion, early detection of abnormalities, mental support for patients, coordination with visiting nurses or primary physicians, preparation for bereavement, and so forth. Because family caregivers had to fulfill these responsibilities alone, they were unable to sufficiently focus on their role as family members, which restricted their ability to cope with the forthcoming loss.

Generally speaking, caregivers initially burdened with a main caregiver role are encouraged to prepare, to some extent, for making decisions on end-of-life care at home while transitioning from the hospital to home. However, for many family caregivers, the act of providing end-of-life care at home is their first caregiving experience. This lack of experience may prevent them from understanding how their anxiety about patients' future course would affect their own lives.

Worden (2009) mentioned that to complete the process of grief, one must fulfill a number of tasks: "to accept the reality of the loss," "to process the pain of grief," "to adjust to a world without the deceased," and "to find an enduring connection with the deceased in the midst of embarking on a new life." In a similar way, anticipatory grief can be a means of forging new family relationships by understanding how they reframe their role within the family after bereavement. Wakabayashi (2008) mentioned that, for individuals engaged in a prolonged struggle with terminal illness, it is possible to

use the remaining time in a meaningful way by restructuring family relationships—including completely restoring them. This would be possible within the home care environment, where family caregivers spend many hours with the patient.

For these reasons, family caregivers must find a way to release themselves from the sense of being trapped in their caregiver role as early as possible, which would help them attend to the role that allowed them to cope with the impending loss.

Promoting a transition between caregivers' roles within a family. The narrative approach was highly effective in helping caregivers transition away from the caregiver role. In other words, by directly approaching the caregiver role through narrative intervention, family caregivers were able to recognize their feelings of being trapped in their role, find release from it, face their own emotions, and cope with loss in their own way. Family caregivers were also able to prepare for the death of the patient by joining with their family members and accepting the reframes in their relationships after the loss. In addition, they prepared themselves to handle the reframing of their roles after the bereavement by adopting the patient's role within the family before the bereavement. The narrative approach helped these patients express their emotions resulting from assuming these new familial roles, and thereby "rehearse" their adaptation to the changing environment.

Both family caregivers attempted to fulfill the caregiver role until bereavement, without realizing that they were trapped in it. They nevertheless felt proud of their accomplishments in taking the role of main family caregiver upon transitioning out of it. It is possible that this feeling becomes a foothold for the smooth progression of their grief. However, as they were not able to fully express their emotions when bound to the responsibilities of the caregiver role, it may be that a balance in the caregiver role and the role best allowing for their coping is necessary.

As noted in the introduction, previous studies conceptualized the progression through the stages of anticipatory grief. Pusa, Persson, and Sundin (2012) said that "the significant others [experience] a great number of stressful emotions. These emotions appeared first in connection with the patients early period of illness and continued, with varying intensity, under the anticipatory and bereavement phase." This suggests that it is a gradual reframing of emotions expressed by family caregivers over time. Anticipatory grief has been considered as a loss in a broad sense, encompassing the past, present, and future, rather than only a loss relating to the specific unavoidable death (Kobayashi, 2008). However, in our study, the process of anticipatory grief refers to the emotions expressed after shifting back to the role characterized by their relationship with the patient, rather than a gradual reframing of emotions over time. This suggests that it is important for caregivers to be able to shift between these coexisting roles, for which the narrative approach can be useful. Nevertheless, it must be noted that effectively transitioning between these roles requires the

family caregiver to recognize why it is necessary on their own; it is ineffective when the transition is forced intentionally by a third party. The narrative approach to anticipatory grief is therefore important because it prompts this recognition.

Nursing care that does not lead to fulfillment of the caregiver role: Effective intervention for family caregivers providing end-of-life care at home. As we have pointed out, a direct intervention for anticipatory grief of family caregivers may be ineffective. Effective support for anticipatory grief is allowing individuals to be released from the captivity of the caregiver role. Nurses generally attempt to understand the family from two perspectives: namely, the family as providers of end-of-life care and the family as subjects of care. Regarding the former, nurses evaluate family caregivers' method of daily nursing care and tend to view these family caregivers on an equal footing with their professional peers. Indeed, because the family caregivers provide care for patients at home for long hours in the absence of a medical professional, they can be regarded as alternatives to nurses in terms of basic medical care and observation. For this reason, nurses should support family caregivers by maintaining an optimal care environment and implementing technical support or various public services, thus ensuring that family caregivers are able to fulfill the caregiver role and become good care providers.

However, because family caregivers are attempting to fulfill this caregiver role, nurses might find it difficult to regard them as the subject of care—namely, as a family member who is progressing toward end-of-life care and must genuinely face the patient for they are caring. Additionally, the nurses have rather limited visitation times for home care. During these visitations, nurse must provide optimal care for the patient while simultaneously providing mental support for the family caregiver. Nurses' responsibilities in family care of a terminally ill patient are generally regarded as sharing anticipatory grief with family members and close friends to help them reach closure (Abe, 2008). However, time and space are limited at home. Thus, any method of suitable mental care for family caregivers must consider such limitations.

It is also important that nurses try to understand what family caregivers think during each visit. However, because family caregivers are continuously providing nursing care, even in the absence of a nurse, they will no doubt experience a buildup of thoughts that ultimately "gush out" as they watch the patient deteriorate. Additionally, as the patient's condition deteriorates, nurses tend to have less time to care for family members when visiting because they must provide more care to the patient. Under these circumstances, it seems necessary for nurses to not only understand caregivers' thoughts but also to help them face end-of-life care by helping them be more aware of their own thoughts and cope with them on their own. The narrative approach can provide such awareness via repeated feedback in a series of small conversations. While it

is not possible to objectively understand one's own thoughts simply through one-way exhalation of them, it is possible through feedback from or conversation with a nurse. Through repeated conversations of this nature, family caregivers can be released from their feeling of being trapped in their caregiver role.

According to the above results, it is important for nurses involved in end-of-life home care to not only provide technical support and teach caregivers to fulfill their caregiver role, but also to support family caregivers so that they can face patients and express their emotions without feeling trapped by their responsibilities as a caregiver.

Limitations

There were only two subjects in this study; therefore, the results are naturally limited in scope. Furthermore, the timing of the interventions were difficult because of time constraints involved in approaching family caregivers who care for patients at the end-of-life stage. In essence, a better method of approaching such subjects is needed in the future, such as by accompanying visiting nurses who know how to apply the narrative approach to patients' homes.

Conclusion

The narrative approach used in this study was effective in clarifying how the anticipatory grief of family members providing end-of-life care at home represents a conflict between the individual's role as a caregiver and their role in relation to the patient. The narrative approach was effective in freeing family caregivers from the feeling of being trapped in their caregiver role, which resulted in them recognizing their own emotions and, in so doing, shift to the role defined by their relation to the patient. This shift helped them to better accept the loss and begin to grieve.

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References

- Abe, M. (2008). Cares and families: The time before death in the community. *Symptom Management in Cancer Patients*, 19, 16–21.
- Burke, L. A., Clark, K. A., Ali, K. S., Gibson, B. W., Smigelsky, M. A., & Neimeyer, R. A. (2015). Risk factors for anticipatory grief in family members of terminally ill veterans receiving palliative care services. *Journal of Social Work in End-of-Life & Palliative Care*, 11, 244–266. doi:10.1080/15524256.2015.1110071
- Casarett, D., Kutner, J. S., & Abrahm, J., & Panel End-of-Life Care Consensus. (2001). Life after death: A practical approach to grief and bereavement. *Annals of Internal Medicine*, 134, 208–215.
- Coelho, A., & Barbosa, A. (2016). Family Anticipatory Grief: An Integrative Literature Review. *American Journal of Hospice & Palliative Medicine*. Advance online publication. doi:10.1177/1049909116647960
- Costello, J. (1999). Anticipatory grief: Coping with the impending death of a partner. *International Journal of Palliative Nursing*, 5, 223–231.
- Duke, S. (1998). An exploration of anticipatory grief: The lived experience of people during their spouses' terminal illness and in bereavement. *Journal of Advanced Nursing*, 28, 829–839.
- Dysvik, E., Natvig, G. K., & Furnes, B. (2013). A narrative approach to explore grief experiences and treatment adherence in people with chronic pain after participation in a pain-management program: A 6-year follow-up study. *Patient Preference and Adherence*, 7, 751–759. doi:10.2147/PPA.S46272
- Fleming, G. G. S. (1998). A comparison of spousal anticipatory grief and conventional grief. *Death Studies*, 22, 541–569.
- Fukura, K. (2015). Sintaikinoushougai wo kakaeru Nouseochuukanja no seikatu no saikoutikunimuketa kango kainyuu no kentou [Investigation of a nursing intervention for supporting re-constructing the life of stroke patients with physical dysfunction]. *Journal of Japanese Society of Nursing Research*, 38, 113–125.
- Ishi, Y., Miyashita, H., Sato, K., & Ozawa, T. (2011). Difficulties caring for terminally cancer patients at home: Family caregiver's and homecare provider's perspectives. *Journal of Japanese Society of Cancer Nursing*, 25, 24–36.
- Kobayashi, H. (2008). Literature review on the definition of anticipatory grief in terminal care. *Journal of the Japan Academy of Home Care*, 12, 32–36.
- Kosako, F. (2012). *Family Nursing*, 10. Tokyo, Japan: Japanese Nursing Association Publishing Company.
- Kübler-Ross, E. (2001). *On death and dying* (S. Suzuki, Trans.). Tokyo, Japan: Chuoukourinsha.
- Lazarus, S. R. (2004). *Stress and emotion: A new synthesis* (H. Honmyou, Trans.). Tokyo, Japan: Jitumukyoiukushuppan.
- Levy, L. H. (1991). Anticipatory grief: Its measurement and proposed reconceptualization. *The Hospice Journal*, 7, 1–28.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141–148.
- Liu, N., & Lai, E. L. (2006). Find a way out: Bereavement support in Taiwan hospice. *Supportive Care in Cancer*, 14, 4–10.
- Moriyama, M. (2002). *Family nursing practice* (1st ed.). Tokyo, Japan: Igakushoin. (in Japanese)
- Morris, C., Simpson, J., Sampson, M., & Beesley, F. (2015). Emotion and self-cutting: Narratives of service users referred

- to a personality disorder service. *Clinical Psychology & Psychotherapy*, 22, 125–132. doi:10.1002/cpp.1870
- Nagato, K., & Sakamoto, A. (2014). *Family Nursing*, 12. Tokyo, Japan: Japanese Nursing Association Publishing Company.
- Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review*, 44, 75–93. doi:10.1016/j.cpr.2016.01.002.
- Okawa, N., Fujita, S., Miyata, R., Togo, J., Toyota, K., Yoshida, A., & Suzuki, Y. (2001). Families' responses to awareness of dying in caring for a terminal cancer patient. *Bulletin of Kochi Women's University Series of Faculty of Nursing*, 51, 1–12.
- Olson, R. E. (2014). Indefinite loss: The experiences of carers of a spouse with cancer. *European Journal of Cancer Care*, 23, 553–561. doi:10.1111/ecc.12175
- Parkes, C. M. (1976). Determinants of outcome following bereavement. *OMEGA-Journal of Death and Dying*, 6, 303–323.
- Pusa, S., Persson, C., & Sundin, K. (2012). Significant others' lived experiences following a lung cancer trajectory—From diagnosis through and after the death of a family member. *European Journal of Oncology Nursing*, 16, 34–41. doi:10.1016/j.ejon.2011.02.004
- Rando, T. A. (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers*. Champaign, IL: Research Press.
- Sheila, M., & Kenneth, J. G. (2004). *Therapy as social construction* (Y. Noguchi & N. Nomura, Trans.). Tokyo, Japan: Kinkoushuppan.
- Suzuki, S. (2003). *Family Nursing*, 1. Tokyo, Japan: Japanese Nursing Association Publishing Company.
- Wakabayashi, K. (2008). Many faces of grief—Anticipatory grief. *Symptom Management in Cancer Patients*, 19, 32–35.
- Watanabe, Y. (2003). *Family Nursing*, 1. Tokyo, Japan: Japanese Nursing Association Publishing Company.
- Williams, A., Duggleby, W., Eby, J., Cooper, R. D., Hallstrom, L. K., Holtlander, L., & Thomas, R. (2013). Hope against hope: Exploring the hopes and challenges of rural female caregivers of persons with advanced cancer. *BMC Palliative Care*, 12, 44. doi:10.1186/1472-684X-12-44
- Worden, W. J. (2009). *Grief counseling and grief therapy: A handbook for the mental health practitioner* (4th ed.). New York: Springer.
- Yanagihara, K. (2008). *Family Nursing*. Tokyo, Japan: Japanese Nursing Association Publishing Company.

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