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Experiences of Spouses of Patients with Cancer from the Notification of Palliative Chemotherapy Discontinuation to Bereavement: a Qualitative Study

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Abstract

Purpose: Many patients with advanced cancer choose palliative chemotherapy. Considering its purpose of palliation and not treatment, it is important to consider the life of family caregivers. Family caregivers who experience bereavement undergo extreme stress, which is particularly high among patients' spouses. The present study aims to clarify the experiences of the spouses of patients at the hospitals in Japan after the notification of palliative chemotherapy discontinuation until bereavement.

Method: We interviewed the spouses of 13 patients who received palliative chemotherapy using a semistructured interview guide. Each spouse was interviewed twice. The interviews were transcribed verbatim, and key concepts were identified using a grounded theory analytic approach.

Results: After the hospital's recommendation for palliative chemotherapy discontinuation, the spouses had "bewilderment over having to discontinue palliative chemotherapy" and experienced "difficulty in facing bereavement." The spouses having "difficulty to give up hope for the patient's survival," felt "bafflement over caregiving at the terminal stage," which would be their responsibility in the future. Further, they had "hesitation in being honest to the patient" and were engaged in "knowing how to live with the patient until bereavement."

Conclusion: Nurses need to encourage the patients and spouses to honestly express how they feel from the early stages of palliative chemotherapy. Furthermore, nurses should help spouses with how they face bereavement. This result may help prevent anticipatory grief, which may lead to excessive stress and emotional distress on the family caregivers.

Keywords: Anticipatory grief, bereavement, cancer, experiences, family caregiver, palliative chemotherapy, qualitative

Introduction

Recently, palliative chemotherapy has been administered to patients with advanced cancer (Roeland and LeBlanc, 2016; Zhang et al., 2018), and many choose to receive this therapy (Pujol et al., 2018). However, since the therapy is aimed at palliation (i.e., symptom alleviation and delaying the occurrence or progression of disease) and not healing, examining how to proceed with the treatment and when to discontinue it is a key issue (Prigerson et al., 2015). This is important because patients undergoing this therapy and their family members who are their caregivers experience a high degree of conflict between their expectations from the therapy and anticipatory grief.

Reportedly, 54% of the family caregivers of patients with advanced cancer receiving palliative chemotherapy lack sufficient knowledge about the treatment, display negative attitudes about disclosing information to the patient with worsening symptoms (Kim et al., 2014), and still have hope for healing (Robinson, 2012). Family caregivers tend to evaluate the patient's QOL as being low and become mentally unbalanced, with a mixture of stress and chaotic feelings (McCarthy et al., 2015). Emotional pain experienced by the family caregivers affects the QOL of the family itself (Choi et al., 2016); moreover, the stress of caregiving may cause the caregivers to develop physical symptoms (Cora et al., 2012). Therefore, providing support to family caregivers is important so that they can understand the patient's state and make appropriate decisions.

The anticipatory grief of the family caregivers may be a highly stressful experience (Coelho and Barbosa, 2017). Their experiences during the patient's battle with cancer affect them even after bereavement (Pusa et al., 2012) and have the potential to facilitate appropriate grief work (Kehl, 2005; Tsai et al., 2016). Conversely, some of these experiences can be risk factors in their bereavement adaptation (Kim and Kown, 2018). Therefore, preventing anticipatory grief involving excessive stress and emotional pain may also inhibit the family caregivers from developing complicated grief after bereavement.

Reportedly, palliative intervention and palliative chemotherapy discontinuation at an early stage of the disease often improve patients' QOL (Greer et al., 2012). However, in Japan, palliative chemotherapy is often continued throughout the end-of-life phase (Aoyama et al., 2017). The family caregivers experience extreme stress, jeopardizing their health (Govina et al., 2015; Fujinami et al., 2015), and the stress experienced by the patient's spouse is particularly high (Asai et al., 2013). Japanese individuals characteristically tend to suppress their emotional expressions (Deeken, 1995; Toyama and Honda, 2016); therefore, a spouse's experiences are generally less recognizable. However, the experiences of the spouses after the discontinuation of palliative chemotherapy have been rarely evaluated and poorly understood, especially in Japan.

Considering the aforementioned context, the present study aims to illustrate the experiences of the spouses of patients with advanced cancer at three hospitals in Japan starting from the time the spouses were informed of palliative chemotherapy discontinuation until bereavement. If we are able to understand the experiences of spouses, we can be better prepared to support them during this time.

Method

Qualitative research using grounded theory analysis was chosen because the present study aims to provide empirical knowledge of the experiences of the spouses of cancer patients. Grounded theory analysis was instrumental in our goal of clearly understanding the nature of spouses' experiences, which still remain poorly

understood.

Sample

First, at three designated cancer hospitals, the patients' spouses were introduced by the physicians who were responsible for the cancer patients' palliative chemotherapy.

The inclusion criteria were as follows: spouses of patients with cancer whose palliative chemotherapy had been discontinued, those who function as caregivers of patients with cancer, and those who were willing to participate in this study. The exclusion criterion was spouses of severely ill patients.

Ethical issues

This study was approved by the ethics review committees of the universities the researchers are affiliated with and the hospitals that cooperated in the survey (ethical approval numbers: 300). Necessary information was provided to the spouses through writing and speech, and the spouses signed a letter of consent.

Data collection

The spouses were interviewed by the first author, who is a female assistant professor who has been trained in qualitative analysis. Each spouse was interviewed twice using a semistructured interview guide. The first interview was between 12 days and 2 months after palliative chemotherapy discontinuation.

The questions were as follows: 1) How did you feel after palliative chemotherapy was discontinued? 2) What have you thought after palliative chemotherapy discontinuation? 3) How have you lived after palliative chemotherapy discontinuation? The second interview was conducted 3–11 months after the bereavement, and the questions were related to the spouse's feelings, thoughts, and way of life until the bereavement.

The interviews were tape-recorded with the spouses' approval. The first interview was conducted in a private room at the hospital, whereas the second was conducted at the participant's home. Each interview lasted for 20–100 (average, 67) mins. A field note was immediately written to record the observation details and interaction process.

Data analysis

Data were analyzed using the grounded theory technique. It is a qualitative research method that uses systematic procedures to develop an inductively derived grounded theory about a phenomenon (Strauss and Corbin, 1990; Strauss and Corbin, 1998).

We (three qualitative research nursing researchers, one cancer nursing specialist, and one cancer treatment researcher) analyzed all the data to completely understand the contents.

First, during the open coding, we segmentalized the data into minimum meanings and coded each segment.

Second, we identified subcategories by comparing the coded semantic units and determined the categories by comparing the subcategories.

Third, we confirmed whether the categories reflected the original segments. During the axial coding, we associated the categories with the data to explain the phenomena.

Finally, we clarified the story line, selected core categories through selective coding, and associated them with

other categories (Strauss and Corbin, 1998).

The data collection and analysis were performed concurrently by theoretical sampling. We interviewed 13 participants twice to confirm and add more data until the data were clarified, verified, and enriched. Credibility was assured by member checking. To increase external validity, we used verbatim transcripts during data analysis to truly reflect the life experiences of the participants in their own words. Reliability was enhanced by continual audits of transcripts against field notes by research team members to ensure consistency throughout the data analysis process. Furthermore, disagreements were discussed to reach a final consensus.

Results

Of the 16 spouses who were introduced, 13 (a–m; 1 man and 12 women) participated in the study. Three spouses declined participation because of their physical condition. We conducted 26 interviews. The patients' spouses experienced bereavement at an average of 2.5 months after palliative chemotherapy discontinuation (Table 1).

We identified 16 subcategories and six categories to describe the experiences of the spouses. *Difficulty to face bereavement* was identified as the core category and was associated with five other categories (Table 2).

Story line: After the hospitals' recommendation for palliative chemotherapy discontinuation, the spouses had A: *Bewilderment over having to discontinue palliative chemotherapy* and experienced B: *Difficulty in facing bereavement*. The spouses having C: *Difficulty to give up hope for the patient's survival* felt D: *Bafflement over caregiving at the terminal stage*, which would be their responsibility in the future. Further, they had E: *Hesitation in being honest to the patient* and were engaged in F: *Knowing how to live with the patient until bereavement* (Fig 1).

A: *Bewilderment over having to discontinue palliative chemotherapy*

The spouses were bewildered at switching to palliative care, given that they were not aware of the disadvantages of continued treatment. They wished for further treatment.

Bewilderment over switching to palliative care

The spouses did not know the merits of focusing on pain relief and thus took a long time to admit the transfer of the patient to the palliative care unit.

“When her condition suddenly worsened, the doctor told me that she should be transferred to the palliative care unit. I did not understand why. (g)”

“I could not understand the purpose of switching to palliative care, just after the three-month treatment. (b)”

Difficulty to understand the disadvantages of continued treatment

The spouses were given an explanation on the disadvantages of continued treatment, and they thought they had no choice but to accept the doctor's decision.

“The doctor declared that he would receive no more treatment because continuing the treatment would only cause more pain to him. I just had to follow the doctor's decision because I would not like him to suffer from pain any longer. (b)”

“The doctor said, ‘We have to stop the treatment because of the side effect.’ I wondered whether he could change

drugs. (a)”

A wish for further treatment

The spouses could not accept treatment discontinuation.

“I could not accept the doctor’s decision to discontinue the treatment because I knew it would shorten my husband’s life. (h)”

“I thought he could live with me at home with care. (f)”

B: Difficulty in facing bereavement

The spouses were shocked by the coming of death. They regretted that they had avoided thinking about bereavement and also felt uneasy about being left alone.

To be shocked by the coming death

When the therapy was discontinued, the spouses who believed that the treatment would be continued were shocked by the coming death.

“To my surprise, the doctor told me that he could not continue the treatment any longer. I confronted the reality of bereavement. (l)”

“I was shocked to know the coming death because I thought he would be able to live longer. (d)”

Repentance of not having thought about bereavement

The spouses had spent most of their time taking care of the patient; therefore, they regretted they had avoided thinking about bereavement.

“Deep in my mind, I didn’t want to accept bereavement as a reality. I knew I had to think about bereavement long before, but I just did not want to. I had avoided it. (i)”

“I am very sorry for not thinking about the future, just hoping for recovery. (j)”

Feeling uneasy about being left alone

The spouses felt uneasy about being left alone after realizing that the patient would die soon.

“I didn’t know what I would do. For the first time, I felt uneasy about being left alone. (m)”

“I feel very uneasy because I don’t have anyone to rely on. (b)”

C: Difficulty to give up hope for the patient’s survival

The spouses kept hoping for treatment to resume and postpone death.

Wish for the resumption of the treatment

The spouses wished that the patients’ condition would improve and treatment would be resumed.

“Others may think my husband will die in near future, but I don’t believe it. I want to believe the treatment will be resumed and continued. (h)”

“I want him to feel better and be treated again. (e)”

Hope for another treatment that will prolong life

The spouses hoped for another treatment to delay bereavement even for 1 day.

“Not providing treatment is one thing, and prolonging life is another. Even if treatment is impossible, I want the hospital to administer infusion of nutritional supplements, for instance, so that my husband can live even for a

little longer. (e)”

“I am asking the doctor to try something helpful apart from administering anticancer drugs. (b)”

D: Bafflement over caregiving at the terminal stage

The spouses could not imagine the patients’ future condition. Not knowing how to care for the patient, they were worried about the financial problems in the future.

Fear about the process until bereavement

The spouses could not predict what the patients would experience; thus, they feared the patients would suddenly experience worse condition or die in considerable pain.

“I am afraid my husband’s condition will worsen to some extent because I have no idea about it. (j)”

“I wonder if the pain will considerably worsen for him to move himself? (k)”

No knowledge on how to care

The worse the patients’ condition was, the more care by the spouses was needed. However, they were at a loss of how to care for the patients.

“I always think about the best care for my husband. However, I never know what to do according to his condition. (c)”

“The doctor said, ‘He can return home.’ But I do not know how to take care of him by myself. (i)”

Mental burden caused by financial problems

The spouses were extremely worried about dealing with the financial problems.

“I chose a private room because I wanted to stay with him. The private room in the palliative care ward costs 10,000 yen per night, which is too much for me. (h)”

“The treatment has cost a lot of money. I cannot only rely on a pension in the future. (l)”

E: Hesitation in being honest to the patient

The spouses regretted that they had avoided talking about death because they wanted to prevent the patients from sensing their nearing death.

Hesitance to ask the patient’s last wish

Although the spouses wanted to know how the patients wanted to spend their remaining time and what the patients’ post-death wishes were, they could not do so because they could not guess how the patients would feel.

“I just cannot ask my wife. It is too cruel. I really want to know how she wants us to treat her, how she wants to spend the time left for her, and what she wants to say to me. (g)”

“I wish to ask him what he wants to do for the rest of life, but I cannot because that will mean death to him. (c)”

Feeling of regret of having avoided talking with the patients about bereavement

The spouses regretted not talking to the patients about bereavement during treatment.

“I’m sorry that I couldn’t talk about bereavement earlier, when he was in a much better condition. What are his post-death wishes? Asking the question at this point is just too cruel. (i)”

“We could have talked about bereavement when he was in good health. (f)”

F: Knowing how to live with the patient until bereavement

The spouses wanted to understand the patients' suffering and let them live as they wish until bereavement.

Sharing the suffering of the patient

The spouses were trying to share the suffering of the patients being aware of the coming death.

"The other day, my husband told me he had written a will. I was surprised to know he had been thinking about death. Tears clouded my eyes as I wondered when he could have done it. (m)"

"He must be enduring much pain, which I have to know as much as possible. (a)"

Letting the patient feel easy

The spouses no longer wanted the patients to have painful treatment and examinations.

"If his life cannot be saved, I do not want him to experience any more pain from drip infusions and other treatments. (k)"

"I want to let him live at home in peace for the rest of his life. (i)"

Fulfilling the patient's last wish

The spouses wanted to fulfill the patients' last wish even if they had to go a little out of the way.

"My husband likes flower gardening. I had him leave the hospital after some negotiation because I wanted him to spend his last days watching the flowers he had grown. (d)"

"He has wanted to go back to his hometown, so I want to inform the doctor regarding his wish and ask for him to be discharged. (h)"

Discussion

We found that the spouses experienced the difficulty in facing bereavement. Based on interview results, we have addressed the issues of decision-making regarding palliative chemotherapy discontinuation, emotional expression, and anticipatory grief below.

Family caregivers find it difficult to understand the limitations of medical treatment (You et al., 2015), and there tends to be little communication between the doctor and the patient concerning a bad prognosis (The et al., 2000). We found that the spouses of patients receiving palliative chemotherapy slightly understood the limits of medical treatment and prognoses. They could not face bereavement seriously until they were notified of therapy discontinuation. The probable background of this situation is as follows: palliative chemotherapy provision for patients until immediately before their death in Japan (Hashimoto et al., 2009), inadequate provision of information regarding palliative care (Morita et al., 2009), and physician's hesitation to talk about death (Mori et al., 2015). Therefore, the spouses did not attempt to decide on palliative chemotherapy discontinuation and had to face the fact of losing their loved ones only after the discontinuation.

Patients receiving palliative chemotherapy are recommended to switch to palliative care at an early stage (Temel et al., 2010), and advance care planning (ACP) is recommended for the patients to express their wishes and intentions early on (Rietjens et al., 2017). However, previous studies have found that patients tend to regard ACP only as an opportunity to express their wishes and intentions (Johnson et al., 2016), and the patients' families tend to go out of their way to support such wishes and intentions (Edwards et al., 2012). How to decide palliative chemotherapy discontinuation is an important issue (Greer et al., 2012). In the current study, the spouses were

bewildered over having to discontinue palliative chemotherapy. These findings suggest the importance of understanding that the spouses cling to the hope of palliative chemotherapy and cannot easily accept bereavement. Therefore, nurses should help the spouses understand the patients' condition during palliative chemotherapy. Furthermore, they also need to help the patients and spouses accept and decide discontinuation of palliative chemotherapy.

The present study showed that being honest toward the patients and openly talking to each other were difficult for the spouses. This attitude probably originates from a Japanese traditional philosophy in which providing harmony in everything is of top priority. Japanese people have a cultural background in which their family caregivers assume the core role in decision-making regarding therapy (Pardon et al., 2012), which often causes emotional burdens and conflicts (Yamamoto et al., 2017). In the cases examined in this study, the spouses regretted having avoided talking with the patients about bereavement and hesitated to listen to the patients' last wish. A previous study revealed the importance of the spouse staying by the side of the patient during the end-of-life days (Mossin and Landmark, 2011). In Japan, however, both patients and their family caregivers who stay by their side often find expressing their feelings to one another difficult (Nakazato et al., 2018). Guessing how the other party will feel is a characteristic of the Japanese population. Most Japanese people are afraid to tell the truth and make the other party feel uneasy or scared. However, family caregivers surely will be sorry, unless they can understand what the patients have in mind and care for them. Therefore, nurses should encourage the patients and spouses to honestly express how they feel before the patients' condition worsens.

Ten subjects in the present study were the spouses of patients who survived for <4 months after therapy discontinuation. After palliative chemotherapy was discontinued, the spouses baffled about caregiving at the terminal stage. Furthermore, they were hesitant in being honest to the patient and were engaged in knowing how to live with the patient until bereavement. The reason is that the spouses felt extremely uneasy: they were aware of the coming death of the patients and had to accept the reality, though they were unable to give up hope. Therefore, nurses need to support the spouses, so that they can accept and deal with the reality. Satisfaction of the family with regard to the end-of-life care and their self-efficacy depends on how less anxious they are (Van Vliet et al., 2013). Therefore, nurses need to help the spouses not to be bewildered over caregiving at the terminal stage so that they can spend quality time with the patients.

In the present study, the spouses' identified experiences, such as the difficulty of facing the patients' bereavement, and were accompanied by excessive stress and emotional pain. However, the spouses did not tend to seek support from others. Therefore, nurses should help spouses deal with their way of facing bereavement. Complicated grief may develop in these spouses, unless they can successfully address these emotions. In addition, social workers, counselors, and support groups should offer support to help care for the spouses who are in poor health.

There are some limitations of the present study. First, the validity of our data may be controversial. Each life is unique, and in this sense, data may not be truly adequate, as there will always be new things to discover. Second, because the target spouses were mostly women, the results obtained may reflect characteristics typical of females. Third, since the duration of therapy and hospitalization varied from patient to patient, another limitation is that the spouses' experiences may differ depending on the person.

Surveying more participants and hospitals and examining a wide variety of cases involving families in many different life situations are necessary to generalize the findings.

Disclosures

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Tables

Table 1 General characteristics of the study subjects

ID	Spouse Age and Sex	Patient Diagnosis	Palliative Chemotherapy Duration	Period from the End of Palliative Chemotherapy to Death
a	63 F	Pancreatic cancer	3 months	2 months
b	60 F	Pancreatic cancer	3 months	5 months
c	69 F	Pancreatic cancer	3.5 months	0.5 month
d	72 F	Pancreatic cancer	8 months	1 month
e	71 F	Lung cancer	12 months	3 months
f	60 F	Lung cancer	16 months	1 month
g	76 M	Lung cancer	19.5 months	1 month
h	65 F	Lung cancer	21 months	3 months
i	65 F	Colon cancer	21 months	3 months
j	61 F	Colon cancer	31 months	2 months
k	65 F	Esophageal cancer	35 months	4 months
l	69 F	Prostate cancer	37 months	3 months
m	80 F	Colon cancer	99 months	5 months

Table 2 Categories and subcategories

Categories	Subcategories
A: Bewilderment over having to discontinue palliative chemotherapy	Bewilderment over switching to palliative care Difficulty to understand the disadvantages of continued treatment A wish for further treatment
B: Difficulty in facing bereavement	To be shocked by the coming death Repentance of not having thought about bereavement Feeling uneasy about being left alone
C: Difficulty to give up hope for the patient's survival	Wish for resumption of the treatment Hope for another treatment that will prolong life
D: Bafflement over caregiving at the terminal stage	Fear about the process until bereavement No knowledge on how to care Mental burden caused by financial problems
E: Hesitation in being honest to the patient	Hesitance to ask the patient's last wish Feeling of regret of having avoided talking with the patients about bereavement
F: Knowing how to live with the patient until bereavement	Sharing the suffering of the patient Letting the patient feel easy Fulfilling the patient's last wish

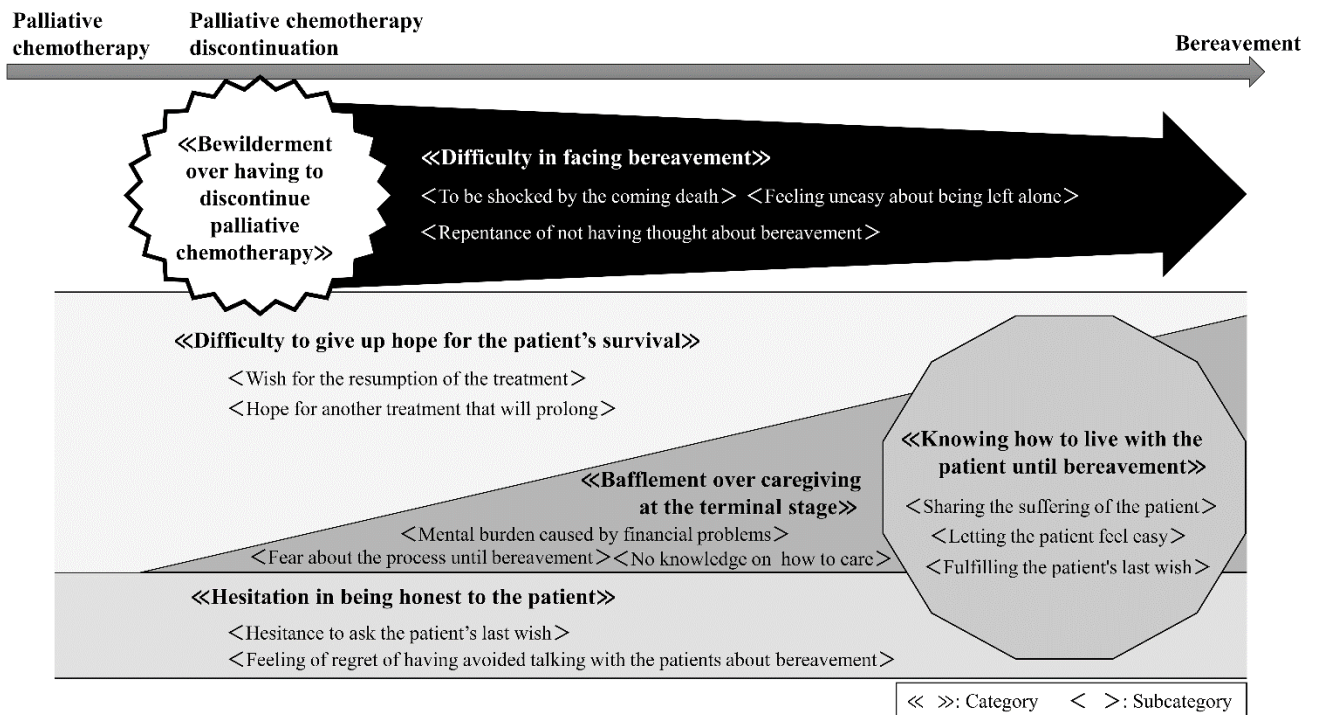


Figure 1 Experiences of Spouses of Patients with Cancer from the Notification of Palliative Chemotherapy Discontinuation to Bereavement