An Occupational Performance Patterns of Family Members of Terminal Cancer Patients: Typology of family palliative caregivers and occupation performance patterns

Seigo Minami¹, Ryuji Kobayashi²

¹ Faculty of Allied Health Sciences, Yamato University, Japan
² Department of Occupational Therapy, Tokyo Metropolitan University, Japan

Abstract:
Objective/Background: In this study, we classified the psychological adjustments of family members of terminal cancer patients using a conceptual structure based on recurring cases. We hypothesised that it is possible to determine the need for intervention on the basis of the occupational performance patterns of the family members.
Methods: The subjects were bereaved family members of cancer patients who died more than a year ago. For our classification system, we adopted code matrix analysis using MAXQDA10 analysis software.
Results: We categorised the 9 cases into 3 types on the basis of functionality with regard to occupation: i) type of continued occupation; ii) type of resumed occupation; iii) type of interrupted occupation.
Conclusions: The categorisation of occupational types assumes that occupation has an effect on the family members’ ability to progress through or alter mental states according to occupational performance patterns.
Keywords: occupational therapy, family caregivers, occupational performance

Introduction

Caretakers of family members with terminal cancer often experience both sorrow and grief following the loss of the patient. Lindemann [1] noted that grief does not only occur only after bereavement; instead, it begins upon the anticipation of death. He called this phenomenon ‘anticipatory grief’.

It is normal to experience grief after the loss of a loved one. However, if this grief continues for an excessive period or disrupts daily life, it is conceivable that the grieving person has fallen into a state of psychological crisis due to pathological grief. Caplan [2] defined such a psychological crisis caused by pathological grief as a situation in which a person faces obstacles against an important goal in life. In other words, the person is in a situation where he tries to solve the problem in the way that he has done habitually, but he cannot overcome the problem.

Occupational therapy is a method to encourage the grieving person to avoid a state of psychological crisis through occupation [3]. To the best of our knowledge, no previous report, other than ours [4], has shown the efficacy of occupational therapy as support for families experiencing pathological grief. In the present study, we studied families who took care of patients with terminal cancer at home and clarified a conceptual structure categorizing the effects of occupation on psychological adjustments of the families using a grounded theory approach [5]. However, our findings were comprehensive and did not reflect the characteristics of individual cases or support specific interventions. Accordingly, we decided to pursue additional data analysis on a case-by-case basis because it is important to clarify relationships between occupational performance patterns and alterations in the mental state. Thus, we supposed that it would be possible to determine the need for intervention on the...
basis of occupational performance patterns observed in each case.

This study coordinated the talk of subjects along six categories obtained in the preliminary research that Minami et al. [4] was contributed to Hong Kong Journal of Occupational Therapy. The purpose of the present study was to clarify the occupational performance patterns and types of occupation of family members of cancer patients using the 'case-category matrix method' in order to identify factors that contribute to alterations in the mental state due to pathological grief.

**Methods**

**Survey period**

The survey period was 5 months, from February 2011 to June 2011.

**Subjects**

The study subjects were family members who provided in-home palliative care for patients with terminal cancer and were selected using convenience sampling methods. The subjects were spouses, children or grandchildren of the patients. They individually interviewed by 4 medical staff members in order. Each patient received palliative care during the final stages of illness. Palliative care focuses on pain management without the use of anti-cancer agents, which are generally administered during intensive care. Moreover, we chose subjects whose family members had died more than a year before participation in this study because we considered a period within 6 months after death to be a ‘grief work’ period, although the duration of this period is reportedly dependent on the age of the caregiver [6, 7]. The Schnabel method was used to qualitatively measure theoretical saturation conditions [8]. The Schnabel method can express a trapping rate in a reasonable viewpoint. To determine whether the theoretical sampling was successful, we calculated and evaluated the trapping rate when new findings began to gradually cease. At this time, we calculated and evaluated the trapping rate when new findings began to gradually cease. At this time, if the label had an overall trapping rate of ≥ 90%, we considered it to indicate theoretical saturation. The study protocol was approved by the Ethical Review Board of Kibi International University (approval number: 10−17).

**Creation of a case–category matrix**

To create a case–category matrix, we placed core categories that were identified in our previous study on the horizontal axis and the cases recruited in this study on the vertical axis. In each of the cells, we provided a paraphrased version of comments from the family member who provided care; these comments were obtained during case interviews regarding the corresponding core categories [9]. In addition to studying the case–category matrix method as a whole, we arranged the details of each case into a story centred on the core categories and classified each case on the basis of similarities between these stories. The core categories were ‘being overwhelmed by pressure’, ‘occupation while living with the illness’, ‘living without being overwhelmed by anxiety’, ‘having difficulties in regulating emotions’, ‘comforting memories of the occupational experiences’ and ‘leading to a change in emotions’ [4].

**Summary of subjects**

In total, 9 cases were included in this study. The Schnabel method yielded a result of 94.8%, indicating that these 9 cases provided theoretical saturation. The attributes of the included cases were as follows: (i) the average [± standard deviation (SD)] period of home palliative care was 7.2 ± 6.9 months; (ii) the average length of time since the patient’s death was 44.8 ± 28.2 months; (iii) the average age of the caregiver was 50 ± 19.9 years and (iv) the average age of the deceased cancer patient was 60 ± 10.8 years (Table 1).

**Results**

We obtained occupational performance patterns from the ‘case–category matrix’ (abridged edition) on a case-by-case basis. As shown in Table 2, case no. 1 fell into the category labelled ‘thoughts are continued’, no. 2 fell into ‘thoughts are continued’, no. 3 fell into ‘work is insufficient’. no. 4 fell into ‘work is insufficient’, no. 5 fell into ‘thoughts are continued’, no. 6 fell into ‘thoughts are continued’, no. 7 fell into ‘resumed former hobbies’, no. 8 fell into ‘resumed former hobbies’ and no. 9 fell into ‘work is insufficient’.

In addition, occupational performance patterns were categorised into 3 occupational types: (i) ‘occupation continued’, (ii) ‘occupation resumed’ and (iii) ‘occupation interrupted’. The distribution of occupational patterns was as follows: (i) ‘occupation continued’: case nos. 1, 2, 5 and 6; (ii) ‘occupation resumed’: case nos. 7 and 8 and (iii) ‘occupation interrupted’: case nos. 3, 4 and 9 (Table 2). Moreover, we found that after the death of the patient, alterations in the mental state were associated with occupation types as follows: in both the ‘occupation continued’ and ‘occupation resumed’ types, alterations in the mental state were promoted, and in the ‘occupation interrupted’ type, alterations in the mental state were incomplete (Table 2).

Here, we specifically describe the occupational performance patterns along with the story of each case, beginning before the cancer patients died.
1) ‘Thoughts are continued’: case nos. 1, 2, 5 and 6

Case no. 1 was a woman who cared for her sick husband. During his illness, the couple spent time gardening, walking, enjoying tanka (a 5-line, 31-syllable Japanese poem) and reciting Chinese poems. ‘One day’, the wife recalled, ‘the doctor told us, “Even if your husband has surgery, I don’t expect that he can survive.” Therefore, my husband told the doctor that he didn’t want to be hospitalised or have surgery. Instead, he wanted to receive home palliative care’. One of the reasons why this patient wanted to receive palliative care at home was that he wanted to help care for his sick mother. His wife, who respected her husband’s decision, devoted her time to care for her husband and his sick mother. After her mother-in-law died, she accompanied her husband to the funeral.

At the funeral, however, her husband’s condition was critical: his lips were blue and he was barely able to stand. His wife supported him and monitored his condition. In addition, she kept a notebook in which she described his fight against his illness. After he died, she re-read her notebook and composed it in tanka form, which had been one of her favourite activities. The son took his father’s camera, photographed scenes of a mountain they had once visited together and shared them with his father. When the father saw the pictures, he happily said, ‘My son continues to pursue my hobby’. The son values the camera till date.

Case no. 2 was a man who cared for his sick father. While his father was fighting his illness, he enjoyed gathering his family members around the dining table for casual conversations. The father reminisced about his life and upbringing, requested that his son look after particular matters after his death, spoke to his relatives about being good members of the society and maintaining a strong family unit and so on. During these heartfelt conversations, the son was able to embrace his father’s passion for photography with his son, which had been one of his favourite activities. The father told his son that he could not take pictures any longer because his condition was becoming prohibitively worse. Thus, the son took his father’s camera, photographed scenes of a mountain they had once visited together and shared them with his father. When the father saw the pictures, he happily said, ‘My son continues to pursue my hobby’. The son values the camera till date.

Case no. 5 was a son who cared for his sick mother. Before his mother died, the couple spent time gardening, walking, enjoying tanka (a 5-line, 31-syllable Japanese poem) and reciting Chinese poems. ‘One day’, the wife recalled, ‘the doctor told us, “Even if your husband has surgery, I don’t expect that he can survive.” Therefore, my husband told the doctor that he didn’t want to be hospitalised or have surgery. Instead, he wanted to receive home palliative care’. One of the reasons why this patient wanted to receive palliative care at home was that he wanted to help care for his sick mother. His wife, who respected her husband’s decision, devoted her time to care for her husband and his sick mother. After her mother-in-law died, she accompanied her husband to the funeral.

At the funeral, however, her husband’s condition was critical: his lips were blue and he was barely able to stand. His wife supported him and monitored his condition. In addition, she kept a notebook in which she described his fight against his illness. After he died, she re-read her notebook and composed it in tanka form, which had been one of her favourite activities. The son took his father’s camera, photographed scenes of a mountain they had once visited together and shared them with his father. When the father saw the pictures, he happily said, ‘My son continues to pursue my hobby’. The son values the camera till date.

Case no. 6 was a daughter who cared for her sick mother. Before his mother died, the couple spent time gardening, walking, enjoying tanka (a 5-line, 31-syllable Japanese poem) and reciting Chinese poems. ‘One day’, the wife recalled, ‘the doctor told us, “Even if your husband has surgery, I don’t expect that he can survive.” Therefore, my husband told the doctor that he didn’t want to be hospitalised or have surgery. Instead, he wanted to receive home palliative care’. One of the reasons why this patient wanted to receive palliative care at home was that he wanted to help care for his sick mother. His wife, who respected her husband’s decision, devoted her time to care for her husband and his sick mother. After her mother-in-law died, she accompanied her husband to the funeral.

At the funeral, however, her husband’s condition was critical: his lips were blue and he was barely able to stand. His wife supported him and monitored his condition. In addition, she kept a notebook in which she described his fight against his illness. After he died, she re-read her notebook and composed it in tanka form, which had been one of her favourite activities. The son took his father’s camera, photographed scenes of a mountain they had once visited together and shared them with his father. When the father saw the pictures, he happily said, ‘My son continues to pursue my hobby’. The son values the camera till date.

Case no. 7 was a woman who cared for her sick son. While his son was fighting his illness, he enjoyed gathering his family members around the dining table for casual conversations. The father reminisced about his life and upbringing, requested that his son look after particular matters after his death, spoke to his relatives about being good members of the society and maintaining a strong family unit and so on. During these heartfelt conversations, the son was able to embrace his father’s passion for photography with his son, which had been one of his favourite activities. The father told his son that he could not take pictures any longer because his condition was becoming prohibitively worse. Thus, the son took his father’s camera, photographed scenes of a mountain they had once visited together and shared them with his father. When the father saw the pictures, he happily said, ‘My son continues to pursue my hobby’. The son values the camera till date.

Case no. 8 was a man who cared for his sick mother. Before his mother died, the couple spent time gardening, walking, enjoying tanka (a 5-line, 31-syllable Japanese poem) and reciting Chinese poems. ‘One day’, the wife recalled, ‘the doctor told us, “Even if your husband has surgery, I don’t expect that he can survive.” Therefore, my husband told the doctor that he didn’t want to be hospitalised or have surgery. Instead, he wanted to receive home palliative care’. One of the reasons why this patient wanted to receive palliative care at home was that he wanted to help care for his sick mother. His wife, who respected her husband’s decision, devoted her time to care for her husband and his sick mother. After her mother-in-law died, she accompanied her husband to the funeral.

At the funeral, however, her husband’s condition was critical: his lips were blue and he was barely able to stand. His wife supported him and monitored his condition. In addition, she kept a notebook in which she described his fight against his illness. After he died, she re-read her notebook and composed it in tanka form, which had been one of her favourite activities. The son took his father’s camera, photographed scenes of a mountain they had once visited together and shared them with his father. When the father saw the pictures, he happily said, ‘My son continues to pursue my hobby’. The son values the camera till date.
mother. While her mother was fighting her illness, the daughter provided in-home palliative care without informing her mother of her cancer. Other family members worked hard to maintain her everyday life without letting her realize that she had cancer, while providing the most devoted care possible all the time. One day on Tanabata (the Star Festival), the mother wrote a tanzaku (a strip of fancy paper to write wishes on) with her family, including her grandchildren. The mother wrote on the tanzaku, ‘Everyone is very devoted to me this year. Thank you. Thank you. Thank you’. The family members who saw that tanzaku were heartbroken. After her mother’s death, the daughter still treasures that tanzaku as it portrays her mother’s feelings of gratitude. Even now, she continues to embrace the feelings of emotional support from the note.

2) ‘Resumed former hobbies’: case nos. 7 and 8
Case no. 7 was a woman who cared for her sick mother-in-law, who had no knowledge of her cancer. Therefore, the woman continued to avoid letting her mother-in-law realize that she had cancer. In spare moments during her illness, the mother-in-law often invited her daughter-in-law to her room and expressed her feelings of gratitude. On the day when the mother-in-law died, the woman was at work and was therefore unable to see her during the final moments of life. She experienced bitterness about this; however, the fact that she was able to offer her mother-in-law a sense of family unity and the memories of her mother-in-law’s expression of gratitude provided her emotional support. The most cherished memory of the woman was that she was able to spend time with her mother-in-law at home until the end, while they mutually supported each other.

Table 2. Abridged edition/case-category matrix.

<table>
<thead>
<tr>
<th>Switching of mental state</th>
<th>type of occupation</th>
<th>Occupational-performance pattern</th>
<th>No.</th>
<th>categories (examples)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Promotion</td>
<td>type of continued occupation</td>
<td>Thoughts are continued</td>
<td>Nos. 1, 2, 5, 6</td>
<td>My husband often woke me up in the middle of the night because of which I couldn’t get sufficient sleep. I suffered from dizziness. I was so tired that I went to the hospital without letting my husband know. After my doctor told me about his cancer, it was difficult for me to accept the reality of the situation. (No. 1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>My husband and I ate, went for walks, took care of the garden, sang “kouta” (a ballad sung to shamisen accompaniment) and together cared for my mother-in-law at home. My husband taught me about gardening and bonsai. Other family members continued singing tanka, which is our hobby, and they accompanied us for walks in the mornings. I wrote about my husband’s condition and the events of each day in detail in my notebook. (No. 1)</td>
</tr>
<tr>
<td></td>
<td>type of resumed occupation</td>
<td>Resumed former hobbies</td>
<td>Nos. 7, 8</td>
<td>My mother-in-law was often scared at night, so she had someone to stay with her and hold her hand. It was painful for me to see my mother-in-law becoming weaker every day. Although care was needed at all times, my mother-in-law did not like the fact that she needed such care. I did not know what to do. (No. 7)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>I harvested in my field and cooked with my mother-in-law. It was refreshing to continue working. (No. 7)</td>
</tr>
<tr>
<td>Incomplete</td>
<td>type of interrupt-ed occupation</td>
<td>Work is insufficient</td>
<td>Nos. 3, 4, 9</td>
<td>My husband lost weight during the week after his doctor told him about his terminal cancer. I was more scared than worried. My husband could not get up on his own at all. I had to pull him up and help him go to the washroom. Our family members were exhausted from taking care of him. (No. 3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Because my husband was self-employed, I helped him with his work. When my husband was hospitalized, he wanted to smoke. I would take cigarettes for him at the hospital. I also helped him move about when he was bedridden. (No. 3)</td>
</tr>
</tbody>
</table>
as a family. Till date, the daughter-in-law continues to appreciate that experience. Since then, she has resumed collecting picture books, a long-standing hobby, because she could not pursue this endeavour during her mother-in-law’s illness. When the daughter-in-law was young, she wished to become a librarian. Since then, she has continued to borrow picture books to read. At present, she is at last able to meet and talk to acquaintances who share her hobby of picture books.

Case no. 8 was a husband who cared for his sick wife. While his wife was fighting her illness, he decided to not tell her about the disease and was committed to spend her remaining time together. His wife wrote about her feelings of gratitude towards the people around her. The husband also filled several notebooks with details of his wife’s life and the events of her illness, while reflecting on her life. After her death, the husband wrote a book detailing his wife’s last years. This book was meant to be a memorial to his wife that would offer a glimpse of his role as a husband as well as his time with his wife and family. The book described his wife’s state of mind while she was fighting her illness and included calligraphy that they had completed together, which reflected the couple’s journey. At present, the husband has resumed his former hobby of photography, which he was unable to pursue during his wife’s illness. He travels in a friend’s car to capture pictures of mountains and neighbourhood scenery, which are shown in an annual exhibition. He has also received some awards.

3) ‘Work is insufficient’: case nos. 3, 4 and 9

Case no. 3 was a wife who cared for her sick husband. One day, her husband visited a hospital because of severe fatigue. After the doctor diagnosed him with
cancer, his wife chose to remain a driving force in his life. She and other family members provided in-home palliative care for a period of 14 days. During that time, the wife spent time with her husband by getting involved in his favourite activities. She continued to encourage him to participate in every activity as well as he could. At the same time, she continued to organise a resume for their printing business believing that he would completely recover. He never gave up trying to recover from cancer, and although he desperately fought and faced his illness, he unfortunately passed away. After his death, his wife closed the printing business and lived at home, choosing to not work any longer. Till date, she sometimes finds it difficult to resume her normal life. The only activities that sustain her are reading and the memory of what her husband said to her while he was fighting his illness: ‘I married you and wanted us both to be happy’.

Case no. 4 was also a wife who cared for her sick husband. While the husband was fighting his illness, his family members were united and supported his endeavours and needs by accompanying him during his drives to the hospital, workplace and home. During these car rides, they reflected on and talked about their family life together, while travelling and walking. In addition, when home palliative care began, the wife expressed a particular fondness for the dining table that had given them a place to enjoy familial interactions. While he was fighting his illness, the husband and wife enjoyed gardening activities such as pruning plants together. The wife stated that she would organise her own state of mind while exchanging emails with her friends and hoped that her husband would continue to fight his illness the following day. Immediately after her husband died, she said, ‘It was great that our whole family cared for him together’. After that, she continued to eat with her family members around the dining table and offered them flowers from the garden. Moreover, till date, she continues to exchange emails with her friends, which was a former hobby that she enjoyed before her husband died.

Case no. 9 was a grandchild who cared for her sick grandfather. While the grandfather was fighting his illness, no one told him that he had cancer. Moreover, the grandmother devotedly cared for her husband, although there were times when she broke down in tears when leaving the hospital. Following this, since no therapeutic effect was expected, in-home palliative care was commenced. As a goal of this in-home palliative care, the family planned to visit a field that the grandfather loved. However, as the grandfather’s physical strength was rapidly deteriorating owing to worsening pathology, they were unable to travel. Even then, the grandmother continued to care for her husband with the hope that he may be able to visit the field at another time. At that time, one of their grandchildren experienced extreme stress, became emotionally exhausted and was incapable of caring for her grandfather any further. Shortly thereafter, the grandchild’s mother was also diagnosed with terminal cancer. Although the mother was aware of her cancer, she cared for the grandfather through his final days. After the grandfather died, all his family members reported feeling like ‘empty shells’. The situation got so out of control that the family members stopped getting along with each other. The grandchild became distressed over her family’s situation, which had fallen apart, and even considered suicide to join her grandfather. Even after the grandfather’s death, the grandmother continued to work quietly on the field that he had loved. Three years after his death, the grandchild got married and had a child, which reunited the family.

Considerations

Occupation was categorised into 3 types: (i) continued, (ii) resumed and (iii) interrupted. Based on these categories, we examined the impact that the occupational performance patterns and the occupation of families of patients with terminal cancer had on alterations in the mental state as follows:

[Occupation continued type] Activities such as gardening, birthday parties, conversations, dining and leisure activities enjoyed with the patients with cancer as they fought their illnesses was a factor in promoting communication. These occasions provided social opportunities for families of patients with cancer, who tended to become absorbed in providing care, and offered opportunities to ameliorate stress [10]. In addition, continuing such occupation after the patients’ death lessened excessive grief and the feeling of sudden change. The immediate family’s image appeared to remain unbroken in the minds of other family members, and the increased improvement in grief suggested that these activities contributed to strengthening familial relationships. Furthermore, it is thought that the experience of working together with others in various ways such as writing a diary, taking pictures, or writing a songbook (not only during but also after the battle with illness) helped family members to embrace their feelings. In a report on family and social functions and other activities that provide family members with a sense of identity and purpose, Keesing et al. [11] noted that after the death of a family member, looking back to the occupation of planning the memorial service and otherwise expressing their feelings appears to help the family members sort out their feelings.
Future challenges and limitations

We believe that it is necessary to further elucidate occupational performance patterns, including pathological grief, experienced by families of patients with terminal cancer. Moreover, to confirm the generalizability and robustness of this model, it is necessary to perform further analysis in a quantitative study design and to measure triangulation. To achieve proper understanding of such situations, it is necessary to implement a research design with qualitative and quantitative measures.

Acknowledgements: We would like to sincerely thank each of the families that participated in the study by giving interviews about painful times in their lives.

References


