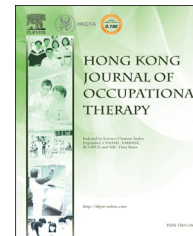




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ORIGINAL ARTICLE

Occupational Experiences of and Psychological Adjustment by Family Members of Cancer Patients



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KEYWORDS

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Summary *Objective/Background:* This qualitative analysis aimed to provide valuable insight into the occupational experiences of and psychological adjustments by family members who act as palliative caregivers. In addition, we also aimed to investigate and clarify these complex experiences and formulate results that are both meaningful and important to the families themselves.

Methods: Families who had lost a family member ($n = 9$) and were part of a palliative treatment support programme were identified through introductions from healthcare workers. They were individually interviewed using both casual questioning and semistructured questionnaires. The data were analysed using the grounded theory approach.

Results: The following six core categories were identified using grounded theory analysis: (a) being overwhelmed by pressure, (b) occupation while living with the illness, (c) living without being overwhelmed by anxiety, (d) having difficulties in regulating emotions, (e) comforting memories of the occupational experiences, and (f) leading to a change in emotions.

Conclusion: Occupational experiences can play a significant role in the psychological adjustment of families of terminally ill cancer patients.

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Introduction

In Japan, the importance of supporting family members of cancer patients and the patients themselves who have made the transition from receiving care in a palliative care unit to receiving at-home palliative care has been emphasized (Akiyama, Matoba, Takebayashi, Nakanome, & Matsubara, 2009; Miyabayashi, Sakaguchi, & Tago, 2007). Families of cancer patients experience a variety of psychological problems, including anticipatory grief while the patients are still alive and mourning after they have passed away (Lorraine & Maureen, 1994; Tsuboi, Matsuwaka, Arai, & Shimizu, 1999). As a result, provision of adequate support services for families of palliative care patients is even more important (Akiyama, Numata, & Mikami, 2007; Shibata & Sato, 2007).

"Occupations" in occupational therapy refers to activities that people perform in their daily lives that give their lives meaning. We felt that there was a need to examine the realities of how family members can assist patients in managing their normal occupation and, in doing so, positively impact their own psychological adjustments.

The field of palliative nursing has explored ways to cope with psychological problems and provide necessary family assistance to bereaved families (Kasai, 2007). However, the role of occupational therapy in palliative care is yet to be extensively explored. Although the importance and effectiveness of occupational therapy for terminally ill cancer patients have certainly been emphasised (Gammage, McMahon, & Shanahan, 1976; Suzuyama, Notoh, & Jinno, 2004; Trump, Zahoransky, & Siebert, 2005), no occupational therapy guides designed for families were found. In addition, occupational therapy for the final period of life is performed in a very small population group in parts of Japan; therefore, further effort in expanding the role of occupational therapy seems necessary (Miki & Shimizu, 2007).

We therefore believed that clarifying the role that occupational therapy plays in families' psychological issues and adjustments by family members can add a new perspective to the area of family-based care, particularly with regard to mourning and anticipatory grief.

For this reason, this study used qualitative research to clarify the ways in which occupations therapy prior to and after death can affect psychological adjustments by family members of cancer patients who received home-based palliative care and the process by which these adjustments occur.

Research approach

Study design

Diers (1979) claimed that adoption of qualitative research was appropriate when the phenomena that occurred were not clearly considered as variables. However, very little empirical data are available from previous research on the participants of this study. Therefore, a qualitative research design was adopted to clarify the very structures of occupation that contribute to the psychological adjustment by family members of cancer patients (Strauss & Corbin, 1998).

Participants

The participants of this study were selected using convenience sampling from families of deceased cancer patients who had received home-based palliative care from the institution that the S.M. was affiliated to. Eligibility requirements were (a) referral from healthcare workers, (b) family consent for the study, (c) the individuals should have cared for a cancer patient who passed away at home, and (d) the deceased patient should have been within two degrees of separation (e.g., spouse or grandparent) to the participant. In addition, during the selection of participants, we considered individuals who had not yet fully finished mourning and chose those whose relatives had passed away during the previous 12 months.

We deliberately selected participants with various backgrounds to obtain a wide range of labels in the theoretical sampling (Strauss & Corbin, 1998). The state of theoretical saturation was measured using the Schnabel method (Matsumura, 2011), which involves interviewing a variety of participants, segmenting them, accumulating labels, and continuously creating categories.

Collection of interview data

Data collection involved visiting participants in their own homes to discuss the aims of the research with the intention of creating an environment in which they were comfortable to speak freely. The actual interviews were also conducted in the participants' own homes. The authors of this study conducted the interviews themselves. Prior to the interviews, information on the attributes of the patients and the participants was collected, including the number of days the patients had spent at home prior to passing away, whether the illness was disclosed, and details of the support provided. The details the interviewer sought were modelled based on a previous research (Minami, Kobayasi, & Ohumatsu, 2011) and information related to the patients' life prior to, during, and after their illness was collected (Table 1).

Methods of analysis

The data obtained in the interviews were transcribed verbatim in the appendix by the primary author of this study. Analysis was performed using the continuous comparative analysis method grounded theory, which is a qualitative research method (Strauss & Corbin, 1998). Raw data were specifically sectioned (or segmented) based on meaning from the transcribed text, the properties (characteristics) and dimensions were enumerated, and each segment of the text was given a simple and expressive code. Similar labels were integrated to generate higher abstraction level categories. The study used the qualitative data analysis software MAXQDA 10 (VERBI, GmbH, Berlin, Germany). The raw data were referred to and the labels were revised many times during their generation.

During the analysis of the qualitative data, specialists with immense experience in the field of health science were asked to provide supervision on a regular basis to ensure the reliability and validity of this study. In

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