

Contents analysis of dementia caregiver's care experiences

Ju-Young Ha¹, So-Young Jeon²

¹ College of Nursing, Pusan National University 49 Busandaehak-ro, Yangsan-si, Gyeongsangnam-do 50612, Korea

² Pusan National University Hospital 179 Gudeok-ro, Seo-gu, Busan 49241, Korea
¹[jyha1028@pusan.ac.kr](mailto: jyha1028@pusan.ac.kr), ²[wjsth64@naver.com](mailto: wjsth64@naver.com)

Abstract

The purpose of this study was to analyze the care experience of dementia caregivers. The results of the analysis showed that a) the formation of a new perspective on dementia care, b) the change of feelings about dementia patients, c) changed in mindset, and d) late regrets. The results of the study showed that dementia caregiver experienced mental and physical difficulties. Therefore, it is necessary to develop instruments that can measure their difficulties through their nursing experience.

Keywords: Dementia, Caregiver, Nursing care, Qualitative research

1. Introduction

The number of patients with dementia is increasing faster than the rate of aging. The prevalence of dementia in 2013 is 9.4%, and the number of demented elderly people is estimated at 570,000[1]. Care for the elderly with dementia takes 2 hours and 45 minutes to 8 hours and 50 minutes and an average of 6 hours or more depending on the degree of dementia. Dementia patient care is not only time consuming but also causes considerable stress due to declining cognitive function [2].

Dementia care should not only experience stress due to work but also experience various conflicts depending on the health condition of the patient, but should maintain socially acceptable feelings. This leads to compassion fatigue, burnout, and emotional labor [3]. In the study of compassion fatigue in dementia nursing practice, it was explained that the concept of compassion fatigue experienced in dementia care practice is the physical and mental burden caused by long-term nursing of dependent dementia patients and emotional attachment to patients [4]. However, this concept analysis is mainly the result of the literature, so it will be necessary to focus on the compassion fatigue experience experienced by caregivers who provide dementia care in practice. In this way, more effective nursing intervention for compassion fatigue felt by providers of dementia care can be achieved. 1

The purpose of this study is to understand the compassion fatigue experience of dementia caregivers in terms of their qualitative research through content analysis. In addition, based on this understanding, we will provide various instruments to discover and describe various meanings and structures and to use it as a basic data for development of instruments for measuring sympathetic fatigue of dementia caregivers.

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2. Purpose

The purpose of this study is to provide a qualitative approach to explore the experience of nursing caregivers of dementia patients in depth and comprehensive from their viewpoints. Thus, the research question to be addressed in this study is "What experiences do you have when nursing dementia patients?"

3. Method

This study collected data through in-depth interviews with experience in caring for dementia caregiver, applying a qualitative analysis of the experience is a descriptive qualitative content analysis research.

4. Sample

The participants of this study were dementia nursing caregivers who have more than 3 years experience in dementia nursing care for the elderly. The total number of participants is 10, including 4 nurses, 3 nursing assistants, and 3 care workers.

5. Data collection

Data collection period for this study was from February to April 2016. The interviews were conducted in-depth interviews for about 3 months. The number of interviews per participant was one. It takes about 1 hour from 1 hour to 1 hour 30 minutes in one interview. Interviewer used an open, semi-structured question format to allow the participants to talk to us at the interview. The question was "What experience do you have when nursing dementia patients?" The place of interview was designated as a hospital counseling room to create an atmosphere that can lead natural conversation with participants. Before starting the interview, we continuously checked and conducted the formation of the trust relationship with the participants, the interview technique, and the use of the observation log for proper and enough data collection.

All interviews were recorded, and after the interview, the recordings were repeated several times. And they were literally transcribed in the language expressed by the participants. Interviewer compared the interviews with other participants and collected them until the data were saturated.

The participant explained the purpose of the interview, the method of research, the recording of the interview, and signed the written agreement to participate in the study. In addition, the contents of the interviews will be used for research purposes only, and the personal circumstances of the individual are kept confidential, the anonymity is ensured, and the participants are informed that they can complete the interview at any time.

6. Data analysis

Data analysis was conducted on data collection and recurring, and continued until data was saturated. The general procedure of qualitative research and the content analysis procedure of Graneheim and Lundman [5] were applied to understand care experience of dementia caregivers.

In order to analyze the data, data analyzed immediately after interview with participants and used it for the next interview and analysis.

Position of the participant, repeated the interview several times in order to understand their experience and understand the meaning.

In order to extract meaningful words, sentences, or phrases that are clearly or hidden from the care experiences of dementia caregivers in the context of the contents of the interview, the contents were analyzed holistically, focused, and analyzed.

Meaningful units were extracted and named as nursing term.

Concepts were compared using similarity, difference, and various analysis frameworks, such as 'viewpoint on dementia', 'temporality', 'spatiality', 'relationship'.

Concepts were abstracted and classified into sub-themes and themes.

Representative statements were selected to reflect well on the derived topics.

7. Results

1) Form a new perspective on dementia care

(1) If you know the symptoms of dementia, it is not harder than nursing patients with other chronic diseases.

Participants stated that nursing patients with dementia were less hard than stroke patients if only the characteristics of dementia patients were recognized. The reason is that, in the case of a stroke patient, there is a possibility of recovery and the possibility of rehabilitation is likely to improve. It is harder to provide nursing if you do not follow it. But if you understand the characteristics of dementia, it is less likely to provide nursing care.

(2) Diseases that extinguish human dignity

Participants were saddened at losing human dignity while watching dementia patients behaving abnormally while nursing dementia patients. It was a difficult to nurse patients who are behaving in uncontrollable and incomprehensible ways with common sense and to feel that human dignity is disappearing.

(3) Be trapped in their own world

Participants feel sick and tired when they are experiencing abnormal behaviors of the dementia patients or repetition of the same behavior, and experiences that do not remember recent work or attack caregivers. On the one hand, they thought that the world of dementia patients seemed to exist, and that they were accepting it as an area that normal people could not understand.

2) Change in emotions for dementia patients

(1) Experience when working in the first dementia ward

Participants provided nursing care in the spirit of serving their parents when they first started working in a dementia ward. And they tried to understand dementia patients' anxiety and the abnormal behavior of the patient, and felt that they were as friendly as their grandfather and grandmother. In this way, participants could see that they had a positive and honorable mind when they first nursed dementia patients.

(2) Experience and emotion felt while providing long-term care

Over time, the emotions that had changed according to the condition of dementia patients have now become dull. They said they were surprised when they found their way of thinking, focusing on making money. And when they treat patients with dementia who refuse to nurse and do not listen to speech once, they also feel hatred. So they tried to exclude their feelings when offered nursing.

3) Change in mindset

(1) Attachment formation with patient

Patients with dementia, a chronic disease, will provide long-term care to the same patient. In this way, dementia caregivers have experience of attachment to a particular patient.

(2) Identify patient and family

Caregivers recall their parents in the process of nursing dementia patients. They feel like 'If my parents get dementia, will they do that?' However, the attitude toward dementia patients is different.

(3) Recall about the patient after work.

Dementia caregivers are thought to be the behaviors of demented patients after work. And the emotions that they felt while they nursed the patients had experiences that affected their emotions.

4) Late regret

(1) Emotion after the patient's death

After providing long-term dementia patients with nursing care, they experienced feelings of regret and regret that they were not able to do well to the patient who was dying. From another point of view, they thought that they would have gone to a good place and expressed a beautiful separation from the patient.

8. Discussion

In this study, we tried to understand the care experience of dementia caregivers in depth and comprehensive from their viewpoints. Participants stated that nursing patients with dementia were less hard than other chronic illnesses if only the characteristics of dementia patients were recognized. And they thought that the world of dementia patients exists and that this disease is a disease that destroys human dignity. They have formed a new perspective on dementia care. They have formed a new perspective on dementia care. This experience has shown that behavioral disorders such as depression, delusions, hallucinations, and anxiety are common in the elderly with dementia, and that behavioral disorders in dementia are different from those in the study of psychological and physical burdens for caregivers [6]. This was different from the idea that nursing would be more difficult due to behavioral problems of patients with dementia. Therefore, a comparative study on the nursing burden between dementia patient caregiver and other chronic disease patient caregivers will be needed.

Dementia caregivers experienced emotional changes for dementia patients over time as they nursed dementia patients. Participants provided nursing care in the spirit of serving their parents when they first started working in a dementia ward. But, as time went on, they began to think that it was simply 'money-making', unlike the first. And that they experience feelings of dullness when they provide care to the patient. This can be a change in the feelings that a dementia patient repeatedly experiences abnormal behavior and provides the same treatment pattern. Therefore, it is necessary to develop a program that can control the emotions of the caregivers.

They have experience of forming attachment with dementia patients. This may be because it provides chronic and long-term care for the same patient. They identified dementia patients with their parents. After work, the patient suddenly appeared and affected my mood and daily life according to the patient's condition. This experience is similar to that of the elderly nursing home residents, who feel empathy when they are caring, experience emotional labor, and ultimately influence their exhaustion [7]. But, there was a difference in that the dementia caregivers of this study had more influence on the emotional part than the physical effect. Finally, participants provided long-term

care to patients with dementia and experienced feelings of regret and regret that they could not do better when the patient died. These experiences are expressed as 'beautiful separation from patients'.

These findings suggest that dementia caregivers have a new perspective on dementia patients, and the longer we provide nursing, the greater the negative emotions we experience. In spite of experiencing these negative feelings, it was found that the long-term nursing provides an attachment relationship with the patient, so that the patient experiences the depressed mood after patient dying. Therefore, instruments should be developed to clearly measure the experience of these caregivers. Intervention studies using telephone counseling have been conducted for family care providers [8], but programs that can control dementia caregiver's feelings are also needed.

9. Conclusion

This study is a study using the contents analysis method of the care experience of dementia caregivers. As a result of the analysis, it was found that there were 4 themes; forming a new perspective on dementia care, change in emotions for dementia patients, change in mindset, and late regret. Dementia caregivers thought that dementia was a novelty, the more long-term care provided to dementia patients, the more they acted differently from the initial attitude, and patient was regretful after death. The results of this study suggest that dementia caregivers experience mental and physical difficulties. Therefore, it is necessary to develop instruments to measure their difficulties through their nursing experience.

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