Research Article

Being in the Midst of a Storm and Labyrinth of Suffering of Family Caregivers' of Patients With Home Mechanical Ventilation (HMV) in Thailand

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Abstract

Advanced medical technology creates hope for ventilator-dependent patients under home-based care. However, family caregiving for patients with home mechanical ventilation (HMV) is associated with a particularly heavy workload. Greater understanding an experience as a family caregiver providing care for a loved one dependent on HMV is needed for the benefit of healthcare providers. The aim of this paper is to analyze in detail 'being in the midst of a storm and labyrinth of suffering', one category of a substantive theory on family caregiving for patients with HMV. This category was developed from a grounded theory study of 22 family caregivers of patients with HMV. Data were collected by using in-depth interviews and participant observations and analyzed by using constant comparison of Strauss and Corbin's version of grounded theory. The study revealed the caregiving process for patients with HMV is as being in the midst of a storm and labyrinth of suffering, which can be explained in the following three sub-categories: (i) feeling incompetent and fear; (ii) managing competing demands and (iii) being overwhelmed. The results of this study highlight suffering as experienced by family caregivers of patients with HMV in Thailand. Understanding of this caregiving process can guide the development of interventions to enhance family caregivers' abilities to provide good care for patients with HMV and to alleviate suffering from the caregiving role.

Keywords: family caregiving; home mechanical ventilation; grounded theory; suffering labyrinth

Introduction

Due to technological advancements in saving the lives of patients with ventilator dependence, the need for HMV is rapidly increasing[1,2], particularly for patients with restrictive neuromuscular diseases, chronic obstructive pulmonary disease (COPD), or obesity hypoventilation syndrome.[3,4,5] Several studies have demonstrated that HMV treatment can improve clinical outcomes such as survival rates[2,6] and health-related quality of life[7]. It has been reported that receiving home care reduces the possibility of nosocomial infections in patients.[8] Furthermore, the use of HMV increases the availability of hospital beds in intensive care units (ICU) for other critically ill patients[8,9] and consequently reduces the costs o institutional healthcare.[10,11]

Families are expected to play key roles in supporting patients with ventilator dependence at home. However, these patients have specific care demands.[12,13] Patients with HMV require individualized care in response not only to basic human care needs, but also technological care needs which further increases the complexity of care.[14,15] As patients with HMV are on tracheostomy tubes, they struggle with communication in conveying their needs.[16,17] Consequently, family caregivers are confronted with caregiving challenges.

Several studies exploring issues related to caregiving experiences among the family members of patients with HMV have been conducted in the past. In one of these studies, Bystedt et al.[18] found that caregivers perceived taking care of patients with HMV as their responsibility. These caregivers have mentioned that their patients frequently developed unpredictable conditions. Family caregivers are aware of the importance of safety when performing complex technical procedures and the potential harm to the lives of their patients[11,15] because they spend 24-hours/day in home-based care for patients with HMV. Previous findings have also demonstrated family caregivers perceive a lack of competence in providing care for patients with HMV.[19] Dywik et al.[20] explored ethical issues related to HMV and found that family members encounter several ethical challenges along the caregiving journey such as decision-making concerning tracheostomy or withdrawal of mechanical ventilation. In addition, conflicts with other family members are commonly reported by family caregivers.[19,21] However, the aforementioned studies were conducted mainly in Western countries where the healthcare systems and technological facilities are quite different from Thailand in terms of advanced life-saving technology and the competency of healthcare professionals. In addition, the caregiving experience in Western and Thai contexts differs due to cultural and social constructs. Therefore, these findings may not accurately reflect the caregiving experiences of the family caregivers of patients with HMV in Thailand.

In Thailand, several studies have explored the caregiving issue. Most of these studies have focused on caregivers who provide care for adult and/or elderly patients with chronic conditions.[22-26] However, the findings from these studies may not be applicable to caregiving for adult and/or elderly patients with advanced-technology dependence. To date, there have been limited reports on family caregiving for HMV patients. According to the literature for this study, one article reported on children at Ramathibodi Hospital in Bangkok in 1995[27], and another study reported on adult patients.[28] In Southern Thailand, one regional hospital had been providing continuity of care for patients with HMV since 2010. Once a patient with ventilator dependence in the study was identified as having a need for HMV, nurses would approach family caregivers for training on how to take care of the patients at home. Bedside teaching and training on the care of ventilated patients has gradually progressed over time. In addition, ward nurses and HMV nurse case manager prepared all the necessary medical equipment. After patient discharge, the home healthcare nurse and the HMV nurse case manager, and sometimes the respiratory care nurse, visited the patients and family caregivers at home.

Since there is a growing number of patients requiring HMV, the study of family experiences in caring for patients with HMV is essential for Thai nurses. Therefore, a naturalistic inquiry was initiated to fill this significant gap and build a theory base for nursing care delivered to family caregivers of ventilated patients at home. The knowledge generated from this study will provide a comprehensive understanding about family experiences in taking care of adult patients with HMV. The findings of this paper stem from a large grounded theory study of family caregiving for patients with HMV, which has been described in detail elsewhere.[29] This theory of family caregiving of patients with HMV explicates a basic social psychological process of 'thriving in family caregiving for patients with HMV' which is evidenced in the following three categories: 1) being in the midst of a storm and a labyrinth of suffering; 2) doing one's best to move on; and 3) achieving blissfulness of mind. This paper reports on category 1: 'Being in the midst of a storm and a labyrinth of suffering'.

Objectives

This paper was aimed at providing a detailed analysis of 'being in the midst of a storm and labyrinth of suffering,' one category from a grounded theory study of family caregivers caring for patients with HMV.

Methods

Design

This report is part of a larger grounded theory study of 'thriving in family caregiving for patients with HMV' aimed at describing and explaining the process of caregiving for HMV patients. This process involves interacting with the multidimensional aspects of caregiving and the coping adjustments made by family caregivers. The root of grounded theory is symbolic interactionism theory, which explains human actions and ways to study human group life from a sociological viewpoint[30]. This approach was mainly derived from the aim to understand social processes, interactions and changes. Grounded theory methodology by Strauss and Corbin[31] was, therefore, chosen to guide data collection and analysis in this study.

Setting

The study was conducted at the patients' homes in Songkhla Province, Thailand.

Participants and Recruitment

According to Corbin and Strauss[32], participants were recruited based on their ability to provide information about varying situations to facilitate the researcher in developing a theory. Purposeful and theoretical sampling techniques were employed in this study. Initially, purposive sampling was applied. The term 'family caregiver' was defined broadly as a blood relation providing care for a patient with HMV. The inclusion criteria for recruiting participants were as follows: 1) being a caregiver of a patient with HMV who lives with HMV well, or is able to be weaned off the ventilator, or died peacefully as perceived by family and, 2) willingness to share experiences. In order to achieve theoretical saturation, a theoretical sampling approach was then adopted. Corbin and Strauss[33] suggested that researchers should look for as many differences as possible in the data by way of contrary cases. Therefore, the researchers in the present study extracted information from the participants' demographic data to generate more comprehensive concepts based on the inclusion criteria: type of caregiver (primary/secondary), role acceptance, type of relationship with patient, caregiver gender and caregiver age.

Twenty-two participants were willing to share their experiences about being family caregivers of ventilated patients at home and defined themselves as primary caregivers (16) and secondary caregivers (6), with 15 being females and seven being males. The ages of participants ranged from 23 to 78 years with an average age of 50. The majority of participants were married (14), while six were widowed or divorced and two were single. The participants had primary school educations (8), which is Thailand's mandatory educational requirement. Three achieved secondary school (high school), six had earned bachelor's degrees, and one had a vocational diploma. In addition, all the participants were Buddhists. The duration of caring for patients with HMV ranged from 1-62 months with the average being 12 months. The participants' employment background showed that seven participants were farmers/rubber planters. Six were unemployed and four participants were business owners (construction, fireworks, laundry and silver plating). Two were street vendors (food and crafts), and the remaining two were official government workers. Household monthly income ranged from 1,000 to 40,000 baht (32 baht=1 USD). The majority lived in rural areas (12 families), and the remaining 10 lived in areas classified as suburban.

Trustworthiness

Four criteria of Lincoln and Guba[34] trustworthiness were obtained. Prolonged engagement and persistent observation were applied. The primary researcher made one to three visits to interview the participants at their homes. The researcher kept handwritten field notes every day. The field notes represent the researcher's personal experiences, reflections and progress while working in the field. A peer debriefing was done to enhance the credibility of findings. To ensure transferability, a detailed description of the characteristics of the participants, contexts and settings in the study was recorded clearly. Data were returned to participants to validate accuracy concerning their experiences. The verbatim transcriptions of audio records and field notes were kept as an audit trail.

Protection of Human Rights and Data Collection

The Human Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand, granted approval for the study (No. 0521.1.05/0603). After receiving institutional ethical approval, the primary researcher met with the nurse responsible for HMV services in a tertiary hospital to approach patients and families who met the inclusion criteria and spoke about the study. Once both patients and families had agreed to participate, the primary researcher briefly described the study procedures in addition to answering participants' questions. Pseudonyms were used in presenting verbatim quotations in this paper. After signing the consent forms, participants selected the dates and times for interviews.

Data collection was conducted from March to October 2016 by using in-depth interviews and participant observation. In general, interviews started with open-ended questions such as, "*How did you feel when you became a caregiver for a patient with HMV?*" "*What do you do to provide care for the patient, and how do you do it?*" The use of open-ended questions allowed the participants to share stories about caregiving experiences. Probing questions followed to encourage participants to provide more details on informative experiences, such as "*Can you give me some examples of things that make you say it was suffering?*" "*What made you feel like that?*". The interviews were conducted in Thai and audio recorded. Each interview took 60-90 minutes. In addition, the researcher observed events participants might have been unwilling or unable to share and situations participants had already defined in the interviews. Hence, participant observations allowed the researcher verify the meanings of terms the participants used in the interviews.

Data Analysis

Data analysis was performed concurrently with data collection guided by grounded theory methodology.[30,31] Analysis was performed in several steps. First, the transcriptions were read through several times in order to get a sense of the text as a whole. Then the entire text was re-read and meaningful statements were highlighted. All meaningful text units relevant to the research objectives were determined and coded. Subsequently, the codes were related to one another and grouped into categories, depending on similarities and differences, and given a description of their manifest content. Sub-categories were then formulated, sorted and abstracted into one category. The research team met monthly to discuss ongoing data analysis and interpretation. Questions and disagreements were reconsidered by returning to transcript data. The interview findings were validated by returning to three participants to ask whether the participants could confirm the descriptions of their experiences.

Findings

'Being in the midst of a storm and a labyrinth of suffering' was identified as the first category of the family caregiving process. The midst of the storm was reflected in situations where participants were encountering and overwhelmed by meeting the competing demands of household work and caregiving tasks while feeling incapable of providing and managing care in addition to fear of the death of their loved ones. Participants perceived their situations as falling into a labyrinth of suffering. Three sub-categories emerged from the participants' descriptions: feeling incompetence and fear, managing competing demands, and being overwhelmed.

Feeling Incompetence and Fear: Condition

Feeling incompetence and fear were participants' initial responses when being informed by the doctor that the patients would be discharged to home with ventilator support. Participants viewed the ventilator as representing advanced technology used for sustaining life and patients requiring ventilation support with a higher demand for care. Several care procedures such as suctioning, ventilating with self-inflating bags and tube-feeding required professional skills they did not possess. These care procedures also needed to be performed carefully and cautiously as they might affect the patient's well-being. Such patients, therefore, should be in the care of health professionals. The participants felt a lack of competence to manage complex technologies and fear that their unskillful care might cause the patients to die. As one of the participants, Chongko, recalled her experiences when she knew that her father would be discharged home with ventilator support.

> *I have never done this before. I don't know how to do it. The nurses tend to think it's not a big job. But it's a big deal for me...I feel afraid and stressed; I can't take care of him. Suctioning is such a big problem for me that it hurts my feelings. I don't know where the catheter is placed. Is he hurting? I am afraid that, if I do it wrong and his condition worsens, it means I will kill him.*

Furthermore, feeling incompetence and fear caused caregivers to experience suffering. Fear of being unable to provide good care and to manage the ventilator well was repeatedly reported by participants. All participants were aware that HMV was important for sustaining the patients' breathing and lives. The ventilator operates with electricity. The participants were worried and afraid of a power outage or a machine malfunction, stating that the ventilator would show alarming signs with English words on the monitor screen when household electricity was shut down. It meant that the patients could not breathe and would die. In the aforementioned situation, the participants stated they did not know how to manage care for the patients in a life-threatening situation at home.

> *An electrical shutdown occurred about 2 a.m. …. I called the Metropolitan Electricity Authority, but nobody responded to my phone call…I said 'Tai Laew'! (exclamation shock) what should I do? I felt very stressed about this situation – didn't know what to do…Sometimes the ventilator monitor screen shows English words in two or three lines. I didn't understand the words. I didn't know which button to press. It should be the job of hospital staff, not me. (Chaba)*

Fear of patient death was also frequently expressed by the participants. The greatest and most frequently encountered fear for the participants was being unable to help and save the lives of the patients if they found the patients had stopped breathing. The participants said that, if something happened and they could not help the patients, they would feel guilty as if they were killing their patients. As Champa shared:

> *It was very fearful for me, I didn't know what to do. It (ventilator) was alarming… sound like this...fea (ventilator sound)!!… I did not know what to do…It was frightening that my mother might develop irregular breathing and stop breathing. I didn't know what to do … I would be upset if my mother passed away. (tears running down her face, quivering voice and sobbing as she wiped her tears). (Champa)*

Similarly, Mali also expressed her fear as follows:

> *It is suffering, like I take care for her (patient) all the time. Then she dies on me. If it happened at the hospital, there would be no problem. It's like I can't get over this situation. But being at home, it will be imprinted in my memory forever…in my heart all the time...Because I live with her. I am afraid that the death of my mom will be imprinted on my mind. (Mali)*

Managing Competing Demands: Action

Although participants felt lack of competence to provide care, they had to move on with their lives and their loved one's life. Managing competing demands reflected the attempts of participants to balance between responding to the caregiving demands of patients and accomplishing housework and/or their own official work. For participants, the patients with HMV were completely dependent and had high care demands. Caring for patients with HMV requires detailed attention. Each day, participants spent nearly 24 hours providing bedside care. Apart from caregiving activities, participants had many household tasks, family responsibilities and obligations that needed to be completed. As Chaba expressed:

> *I have to manage my roles both as caregiver and family member. As a caregiver, I have to keep my eyes on my father (a patient with HMV) all the time, while the roles of wife and mother who takes care of her family/children cannot be neglected. I feel tired, particularly on busy mornings. My children will go to school, I have to prepare their uniforms and food, then take them to school. Meanwhile, I have to give my father, who can't move, a sponge bath. I do all these things everyday... I do it all*

> *alone! Complete the sponge bath, change my father's sleeping position from left to right, change the bed sheets...(sigh)...I am tired! After I have done everything for my father (patient), I also have to provide care for my mother who is frail and elderly.*

In addition, some participants worked full-time jobs while others took care of other family members and raised their children. However, caring for the patients was always the first priority.

> *I can't be only a caregiver. I have to work, because I have to earn money to support myself and my family. One person has to do two things at the same time. I can take leave from work, but I can't take leave from providing care... I have to do this as my top priority. (Champee)*

Being Overwhelmed: Consequence

Being overwhelmed by caregiving is a consequence of managing competing demands. Being overwhelmed is defined as feelings of tension in caregiving situations as the result of psychosocial interactions between participants and patients or other persons. The participants put their patient's needs as their top priority, eliminating other social activities deemed unimportant compared to caregiving. One participant shared her difficulties and suffering in managing competing demands. She mentioned that caregiving situations made her stressed and angry.

> *My life is chaotic; I don't deny the caregiving role. I feel tired, but I am always focused on my father (patient)...I feel stressed with both my work and caregiving role. I sometimes get mad, but I keep telling myself I have to do it...I have to solve the problems in my house such as food and meal needs. One day, I drove home after work and found that there was no food for my dad. I said angrily to my mom (who is a secondary caregiver), 'Why didn't you tell me before I came back home? I have to go out into traffic.' This event made me so stressed... I was tired and angry (tears flowed from her eyes), I have to deal with so many responsibilities; I am always so busy. I complained to my mom, and she became angry at me, saying I didn't take care of my dad (patient) enough. Constant quarrelling with my mom is another source of stress for me. (Chongko)*

Being full-time caregivers of ventilated patients at home affected the participants' well-being. Fatigue, weakness, low energy and lack of motivation in daily life were usually reported by participants as the consequences of the overwhelming caregiving situations.

> *I feel tired all the time. Each day, I grow more tired. Sometimes, it is fatigue and tiredness...I feel weak. It's discouraging, I feel like my muscles don't have the strength to wake up in the morning...I'm downhearted and discouraged. Some days, I don't want to wake up to do anything for him (patient). I don't want to give him a sponge bath. (Chaba)*

Some participants indicated that they never got enough sleep since they had to keep their eyes on patients most of the time. Sleep patterns were interrupted by caregiving activities such as: suctioning or noise from ventilator alarms and patients' coughing. Several times, the family caregivers had to wake up hourly to check the ventilator to ensure that their patient was still breathing and that the ventilator was functioning. This caused them to feel tired and sleepy daily. Some participants shared their sleepless experiences:

> *I am very tired. At night, I have to suction to clear secretions in the tracheostomy tube... I'm always so tired. Some nights, she (patient) sleeps but the other nights she doesn't. I have to wake up for suctioning to clear her airways two or three times a night. Sometimes, I have to get up to massage her. Afterward, she feels better. Then I can go to sleep. (Champee)*

Overwhelming caregiving experiences led the participants on a quest for the meaning of care. Whenever they felt overwhelmed and exhausted, many questions would arise and were left unanswered: Why do I have to be a caregiver? Why me? Why not other family members? What is happening in my life? These questions kept echoing in their minds. As Chaba, a young adult female participant providing care for her HMV father expressed her experience in searching for meaning in care said:

> *I, myself, tried to search for answers. Ah! While my father (patient) has many children, why didn't anybody else come to help? I've tried to answer the question for myself. It's never ending...Why? Why me to take care of Father? I have never done it before. I still want to travel. I still have many things to do...many concerns... I don't have this kind of experience. Since I was born, I have never seen this machine. I didn't study in this field. I have no idea, but I have to do it. ...But, how did this happen? What is it happening in my life? ...As soon as I knew I was the one, I was furious. I often said to my father. You have eleven children, why only me? I felt hurt and disappointed in my siblings.*

Chaba elaborated further that taking care of her father with HMV was like rowing a boat in the midst of a storm of caregiving and household demands. She did not know when it was going to end. These feelings and questions initially affected the quality of care provided at home as well as the patient's well-being.

> *(My life) is like a boat floating in the ocean ...and I keep rowing the boat continuously and endlessly. I can't see the shore...that's my father. We cannot keep him going (his life)... The doctor told us that he can live for three more years. Sometimes, you cannot tell or predict...I don't know how long he will live. Now, it's been two years, so how long will he be alive? .... I can't say when the end will come and where the end is. Whenever it happens, it will happen. If it (the boat) reaches the land, whenever will be, will be. ...I must continue to row until the end, wherever that is. I know that day will come...but I don't know how long it will take...in months or years. (Chaba)*

Discussion

Being in the midst of a storm and a labyrinth of suffering was identified as one of three main categories in the grounded theory of the process of family caregiving for a loved one with HMV. The midst of the storm represented the state where caregivers had to manage the caregiving demands of patients with HMV together with responding to personal and family needs. However, these caregivers also suffered from being unable to fulfill these needs. The following three sub-categories were identified under this category: feeling incompetent and fear; managing competing demands; and being overwhelmed.

The findings highlighted that feeling incompetent and fear constantly appeared when the doctor prescribed HMV for the patients. The caregivers perceived that their loved ones remained acutely ill. These patients depended on advanced technology and needed professional care. The participants felt that they lacked the knowledge and necessary skills required to provide adequate care for their loved ones with HMV. Lindahl and Lindblad[35] found that family caregivers of patients with HMV perceived the caregiving experience as hard work and a process of learning to develop appropriate knowledge and skills. Family caregivers of patients with HMV had to learn more about the seriousness of the patients' conditions. Due to lack of competence, the family caregivers' unskillful caregiving activities could have caused the death of their loved ones. Fear of patients' death was also commonly expressed by participants. Neimeyer[36] noted that death is considered one of the major components of the existential beliefs of every person. Fear of death is a natural reaction to confrontation with death[37] as spiritual suffering. Constant awareness of a patient's death may be raised in stages of caregiving while providing care at home. There are several critical stages and events that trigger a stronger fear of patient's death such as, power failure, ventilator malfunction and patients' progressive illnesses[38] that might cause patients to stop breathing and die suddenly. Furthermore, the caregivers could not help or take the patient to hospital. Caregivers who indicate greater fear of patient's death have greater suffering, while caregivers who have adverse expressions tend to have less suffering and be capable of accepting death[39,40].

Managing competing demands reflected the attempts of these caregivers to manage the competing demands of their multiple roles. Family caregivers of patients with HMV felt they suffered. Not only did they have a 24-hour caregiving role, but also had other family roles as mothers, wives and income earners. The caregivers experienced both working outside the home and providing care for their loved ones at home. With current societal changes in Thai family structure (extended to nuclear), changing cultural lifestyles of younger generations, social pressures and financial problems, both men and women have to work outside or away from their homes to provide financial support for their families[41]. These multiple roles and potentially conflicting obligations can cause psycho-emotional stress, more physical health illnesses and an increased risk of caregiver mortality[42-44]. These data are consistent with a report by Grant and Graven[45] in which the findings of a study on an integrative review of the problems experienced by informal caregivers of patients with heart failure described caregiving as performing multifaceted activities that revolve around heart failure demands. Balancing caregiving and work roles creates conflict and strain in addition to a high level of responsibility regarding the care, safety and caring needs of patients[46]. Managing household tasks, communicating with health professionals and providing emotional support for patients, were tasks the caregivers also reported as a burden.

The findings from this study further reflect that the caregiving process of patients with HMV was a major disruption in caregivers' lives. While these caregivers tried to manage and balance the competing demands of multiple roles, most of the caregivers' time was spent with patients. They struggled to manage medical technology such as ventilator functions, changing the tracheostomy tube and assessing and supporting when the patients' symptoms worsened.[47,48] Concerning the reasons for feeling overwhelmed, Moradian et al.[49] revealed that caregivers providing care for patients with HMV felt fatigue and distress because the caregiving responsibility consumed most of their time. The caregivers also had feelings of restriction and disconnection or isolation from social activities with their friends.[50,51] During the course of a lifetime, low energy and less motivation usually occur in daily life. In addition, higher levels of stress are significantly associated with lower levels of quality of life and well-being.[52,53] Family caregivers require more professional support to create a smoother everyday life adjustment and relieve their ever-increasing burdens.[53,54]

Finally, the caregiving situation raises spiritual 'Why me?' questions for participants. These data are similar with the cognitive theory of Taylor[55] on adaptation to threatening life events. People who ask the aforementioned questions might be experiencing stress in the process of finding personal peace of mind. Dervin[56], expressed that the question, 'Why me?' occurs in persons to make sense of life-altering experiences. Meanwhile, White[57] described the critical elements of story construction by using the terms 'landscape of meaning'. Providing care for a loved one with HMV impacts the family caregiver as well as the individual. Asking, 'Why me?' is actually telling a meaningful story that has a beginning, middle, and end and serves as part of helping family caregivers construct a new "destination map"[58] as they seek motivation to use their remaining abilities to provide care for ill family members and sustain life as fully as possible, despite obvious uncertainties. However, a number of family caregivers were not asked questions about the meaning of their critical situation and the above question. Others discuss how their ideas respecting 'Why me?' have changed over time. Russell et al.[59] noted, a few state that asking such questions brings its own stress. Consequently, timing may be important in predicting the impact of the search for meaning. It also makes sense to consider the ways in which families make sense of their experiences when a family member is ill.

Conclusions and Implications

This study highlighted the caregiving process for patients with HMV. The findings enhance understanding of the suffering of these caregivers. Intervention programs for developing educational homecare programs to enhance caregiving competencies and psychosocial nursing programs to reduce the caregiving burden are recommended. Further research is recommended to advance understanding of the impact of the caregiving experiences faced by family members' patients with HMV in urban settings.

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