Thriving in Family Caregiving: A Grounded Theory Study of Thai Family Caregivers of Patients with Home Mechanical Ventilation (HMV)

Monthira Udchumpisai

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy in Nursing (International Program)
Prince of Songkla University
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I hereby certify that this work has not been accepted in substance for any degree, and is not being currently submitted in candidature for any degree.

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ABSTRACT

Home Mechanical Ventilation (HMV) has become the most significant life sustaining therapy for patients with chronic respiratory failure condition. Caring for persons with life sustaining technology dependence at home is challenging. Family caregivers play a key role in providing care at home. However, little is known about the caregiving experience for Thai patients with HMV. This study aims to explore family caregiving process for Thai ventilation-dependent patients at home.

Straussian grounded theory was employed to explore the phenomena of family caregiving experiences and the contextual influences of careging on responses to care management. Participants were 22 Thai family caregivers who provided care for the loved one with HMV in Songkhla province, Thailand. In-depth interviews, participant observation, and field note were the methods of data collection. Constant comparison and coding process were the basic analysis method.

The substantive theory developed in this study was the model of thriving in family caregiving for the mechanical ventilated patients at home, transformation of family caregivers' experiences when dealing with caregiving demands was an important process to help them overcome difficult caregiving conditions. Three categories in the process of thriving in family caregiving were identified: being in the midst of a storm and a labyrinth of suffering, doing one’s best to move on, and achieving blissfulness of mind. Family caregivers who could thrive in caregiving for their loved one with HMV were able to live life harmoniously in balance and happiness.

Knowledge gained from this study can be used to improve family caregiving for patients dependent on HMV by promoting them to achieve the thriving in care. This model can be used as basic information to develop a specific intervention program for patients with HMV and to motivate healthcare providers to engage in effective technology care at home.

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CHAPTER 1

INTRODUCTION

Background and Significance of the Problem

The demand for home mechanical ventilation (HMV) has rapidly increased due to technological advancements of patients who suffer from chronic respiratory failure (Garner et al., 2013; Povitz et al., 2018). In Thailand, invasive HMV was formally established with children at Ramathibodi hospital in Bangkok in 1995 (Preutthipan, 2000). Since 2010, care for chronic respiratory failure in adult patients with HMV has been in clinical practice at Hat Yai hospital in Songkhla province. Recently, the number of HMV patients has been significantly increasing. According to a Hat Yai hospital report from Chaikul (2012), respiratory failure patients with weaning difficulties who required long-term mechanical ventilation care reported 4, 9 and 15 cases per year for years 2010, 2011 and 2012 respectively. In 2017, home health care providers reported 35 cases of HMV dependent patients.

Home mechanical ventilation (HMV) is an invasive form of mechanical ventilation via a tracheostomy provided to the patient at home (Lewarski & Gay, 2007; Windisch, 2013). It has been a treatment for chronic respiratory failure patients particularly with restrictive neuromuscular diseases, chronic obstructive pulmonary disease (COPD), or obesity hypoventilation syndrome (King, 2012; Make et al., 1998; Windisch, 2013). Patients suffering from these conditions require long-term ventilation support. The goals of HMV are to improve alveolar ventilation, reduce symptoms and enhance a better quality of life (Chang, 2014; Huttmann, Storre, & Windisch, 2015).

Consequently, it is said that HMV provides hope for a patient and their family for sustaining the patient's life in a home setting (King, 2012).

Several studies have reported on the advantages of HMV treatment. Research data suggests that the use of HMV will increase because of its documented benefits for patient and economic pressure to reduce hospital length of stays. HMV treatment can improve clinical outcomes, e.g., patient survival rates (Povitz et al., 2018; Tagami et al., 2014) and health-related quality of life (MacIntyre, Asadi, McKim, & Bagshaw, 2016). It has been reported that receiving home care reduces the possibility of nosocomial infections in patients (Downes, Boroughs, Dougherty, & Parru, 2007). Furthermore, the use of HMV increases the availability of more hospital beds in intensive care units (ICU) for other critically-ill patients (Downes et al., 2007; Nava & Vitacca, 2013) and consequently reduces the costs of institutional healthcare (Ballangrud, Bogsti, & Johansson, 2009; Guber, Dipl, Chen & Israeli, 2002). In addition, the home represents a harmonious and desirable place for care (Lindahl et al., 2005). Living at home improves the patient's quality of life and for their family (Lindahl, Liden, & Lindblad, 2010). A study by Yamaguchi & Suzuki (2013) reported that HMV enhances social relationships between patients and their caregivers.

Although HMV treatment is beneficial for both patients and hospitals, it does significantly impact and requires greater support from their families and healthcare providers (Dyrstad, Hansen, & Gundersen, 2013; Fex, Flensner, Ek, & Soderhamn, 2011; Israelsson-Skogsberg & Lindahl, 2017). These 24-hour technology dependent patients require tracheostomy ventilation. According to Tobin (2013), the management of ventilator-supported patients involves positioning, pain control, humidification, airway secretion suctioning and psychological support. Since these patients cannot effectively breathe on their own, respiratory assistance devices are essential to their life support. Some technical problems such as power failures, ventilator malfunctions or circuit obstructions may cause ventilator failure (Simonds, 2016). As a result, patients need to be continuously monitored and provided support. In addition, Tsay and colleagues (2013) conducted a meta-synthesis review on the experiences of adult ventilated patients. These findings pointed out that patients had both psychological and spiritual needs, and valued caring relationships as essential for coping and living well with a ventilator. However, HMV patients struggled with communication in conveying their needs to their family members (Laakso et al., 2014; MacIntyre, 2012). Dreyer, Steffensen and Pedersen (2010) concluded that patients with HMV require individualized care corresponding to their needs not only basic human care, but also technological care which advancement. Yet, technology increases the complexity and the difficulty of caregiving (Suncho et al., 2011).

Since most of these patients cannot perform self-care, they need further assistance with the activities of daily living (ADL). It has been accepted that family caregivers must play key roles in providing this care for ventilation-dependent patients at home. Family caregivers are expected to manage day-to-day living for patients with respiratory diseases and disabilities, identify and timely respond to complications, and competently use respiratory equipment and follow procedures safely (González et al., 2017; Dybwik et al., 2011b)

To date, several HMV studies have been conducted that explored issues related to patient caregiving experiences of family members. Bystedt, Eriksson, and Wilde-Larsson (2011) found that caregivers perceived that taking care of a HMV loved one was their responsibility. These caregivers had to provide 24-hour home-based care for their loved ones who frequently developed unpredictable conditions. Additionally, they were keenly aware of complying with safety protocol when performing complex technical procedures and the harmful repercussions to the patient if mistakes or errors are made (Israelsson-Skogsberg, & Lindahl, 2017; Suncho et al., 2011).

Concurrently, a recent study reported that family caregivers perceived a lack of competence in providing care for their HMV dependent loved ones (Dywik, Nielsen, & Brinchmann, 2011). Dywik et al. (2011a) explored the ethical issues related to HMV. They found that family members encountered several ethical challenges during the caregiving journey such as the decision-making about accepting the tracheostomy procedure, initiating HMV care, designating a primary caregiver, or the legality of withdrawing mechanical ventilation. The decision to remove or stop mechanical support signifies terminating the patient's life (Geiseler, Karg, Borger, Becker, & Zimolong, 2010) and requires further support or evidence from healthcare specialists (Dybwik et al., 2010). Numerous or recurring conflicts with other family members is commonly found among family caregivers (Dywik et al., 2011a; Dybwik et al., 2010).

In another study by González et al. (2017), family caregivers of patients with HMV normally perceived and considered their provision of care to be emotional, physical, social and financial burdens (Nonoyama et al., 2018; Paruk et al., 2014). As a result of managing complex care for technology-dependent individuals at home, devotion to care and attention to their loved one's needs have its own costs in the caregiver's daily life (Huisman-de Waal et al., 2007; Evans et al., 2012). Dybwik (2011b) stated that HMV care precedent by the caregivers over other family member lives well as time, attention, and focus away from other family members and their own needs and desires.

Moreover, families find it difficult to give meaning to their experiences and fully understand the consequences of such significant lifestyle adjustments. Furthermore, it has been reported that the family caregivers of HMV patients suffer major time restrictions which has negative impacts on their physical and mental health (Evans et al., 2012; Paruk et al., 2014), and is associated with high levels of burden (Falkson et al., 2017; Marchese, Lo Coco, & Lo Coco, 2008). With negative consequences, family caregivers need support from healthcare providers in order to reduce their levels of burden (González et al., 2017).

It can be concluded that previous study findings provided a picture of negative impact of caregiving experiences while there was a lack of positive experiences of family caregiving for the loved one dependent on HMV. Based on the researcher's observations of family caregivers who cared for their HMV dependent patient, both the family caregiver's burden and their happiest from the caregiving role were revealed. In addition, most previous studies were conducted 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. The caregiving experience in Western countries differs culturally from Thai contexts. Assigned functions and roles within Western and Thai societies are different. Therefore, Western study findings does not accurately reflect the caregiving situation in Thailand. Devout Thai family caregiving is the key to program success. Caregivers who can sustain and balance their family role is essential to the process. Nurses then can gauge and assist families caregiving on how to provide better quality of care and also help caregivers achieve well-being.

According to current literature, it can be concluded that individuals requiring HMV represent a small but an increasing group in the society. It is especially true for Thailand. No studies on the caregiving experiences in the HMV adult patient population have been conducted in Thailand to date. There still remains a lack of the knowledge regarding the family caregiving experiences involving patients with HMV. Dybwik et al. (2011b) recommends the need for further study in this population, especially for the caregivers' experiences. One of the roles for nurses is to help restore or maintain the stability of the family and assistance the family members achieve their highest level of functioning possible (Denham, 2003).

According to Lee (2005), caregiving is not only a task activity, but also a process that interacts with multi-dimensional aspects of caregiving and coping adjustments made by family caregivers. Therefore, the researcher aims to explore the processes of caregiving from the perspectives of the family caregivers of patients with HMV and to construct an emerging caregiving theory. The grounded theory approach is suited to conceptualize the caregiving process in Thai families providing care for patients with HMV. The understanding into these experiences will be an important resource for hospital staffs in establishing HMV discharge plans and obtaining a better understanding of the sustainability of care offered by family caregivers. The local healthcare service providers in the patient's community can also use this data to offer a better continuity of care plan for both the family and ventilated patient.

Research Objectives

The purpose of the study is to generate a substantive theory that describes and explains the successful caregiving process based on the perspectives of family caregivers of patients with HMV. The grounded theory method described by Strauss and Corbin (1998) was used to achieve this aim.

Research Questions

1. What is the successful family caregiving process for patients requiring home mechanical ventilation?
2. How do family caregivers move forward and harmonize the caregiving role into their own daily life?

Significance of the Study

Knowledge from this study used to generate a theory grounded on the family caregivers' perspectives based on their caregiving experiences for their loved ones with HMV. The theory of successful family caregiving benefit healthcare providers in understanding the aspects of the caregiver's role and how family caregiver deals with and tries to solve the problems of caring for patients requiring mechanical ventilation at home. In addition, the consequences of a successful family caregiving theory provide support for both the family caregiver and the ventilated patient at home. This understanding may enable healthcare providers be more culturally sensitive and develop better nursing care interventions to meet the caregiver's needs. Lastly, the ultimate contribution of this research consists of providing useful information to the caregiver of a technology-dependent patient in a home setting. For Thailand, this research can serve as a springboard in developing specific national health policies.

CHAPTER 2

LITERATURE REVIEW

There are arguments regarding the role of a literature review in qualitative research, including the grounded theory inquiry. Glaser (1978) disagrees with conducting an extensive literature review before entering the field. He asserts that discovering a theory that fits the data should be the goal, and that the researcher should aim to work in a real-world situation (Glaser & Strauss, 1967). Extensive reading may influence the researcher to develop pre-conceived ideas resulting in the presentation of a theory, which overlays existing data and analysis. In other words, a theory developed according to the grounded theory methodology should emerge from collected data, not from substantive theory (Heatha & Cowley, 2004).

On the other hand, Strauss and Corbin (1990) have argued that specific understanding, past experience and literature are useful in stimulating the researcher to develop a theoretical sensitivity to data. In addition, Holloway and Wheeler (2010) suggested that a literature review is the first step to conducting a study; this first step is also related to several advantages. Literature reviews help researchers discover existing knowledge about their subject of interest and acknowledge those who have worked in this area. They also help identify gaps of knowledge and describe how certain studies contribute to the existing knowledge on specific topics. Furthermore, literature reviews help researchers avoid duplicating others’ work. Lastly, literature reviews contribute to and reflect upon interpretations of research questions.

It can be concluded, therefore, that beginning with an extensive literature review may be inappropriate for qualitative research, while starting without any ideas about what has already been done in the field can be hazardous. This chapter provides a brief overview of the literature related to the study. It is not difficult to see that the context of a healthcare system affects family caregiving for patients on HMV, while the patients' caregiving demands also influence the caregiver experience. Consequently, a brief overview of the long-term care policy related to caring and support for patients with HMV will be presented in this chapter. Next, the concept of family caregiving will be addressed. Additionally, family caregiving for patients on HMV in the Thai family context will be discussed. Lastly, a review of grounded theory methodology will be presented.

Outline of the Literature Review

Policies Related to Care and Support for Patients on HMV

- Definition and advantages of HMV
- Global policies for long-term care
- National policies for long-term care
- Long-term care services related to caring for patient on HMV

Concept of Family Caregiving

- Definition of family caregiving and family caregiver
- Characteristics of family caregiving
- Consequences of family caregiving
  - Family caregiver burden

    - Positive aspects of family caregiving
  - Factors related to family caregiving experiences
  - Thai socio-cultural perspective on family caregiving
    - Hierarchy relation
    - Traditional gender roles
    - Religious beliefs
  - Changes in social and family structure in Thai society

Family Caregiving for Patient Dependent on HMV

- Caregiving demands in patients on HMV
- Family caregiving process and experiences with patients on HMV
- Nursing interventions to promote family caregiving

Grounded Theory

- History
- Evolution
- Philosophy
- Other qualitative methodologies
- Grounded theory in nursing

Summary

Policies Related to Care and Support for Patients on HMV

The number of patients living with HMV is increasing worldwide (Garner et al., 2013; Kim & Kim, 2014; Rose et al., 2015). Therefore, an understanding of the definition and advantages of HMV as well as the national long-term care policies regarding this topic provides a beneficial perspective in the development of sustaining care and support program for patients on HMV.

Definition and Advantages of HMV

According to Windisch (2013), HMV refers to long-term invasive mechanical ventilation at home, which requires the insertion of a tracheal tube following tracheostomy. It is used as a treatment option for patients with chronic respiratory insufficiency with any failure of the respiratory system or can occur because of chronic critical illness such as restrictive thoracic disorders, chronic obstructive pulmonary disease (COPD), obesity hypoventilation syndrome, and neuromuscular diseases (King, 2012; Make et al., 1998; Rose et al., 2015; Windisch, 2013). These hospitalized patients cannot be weaned off mechanical ventilation, but are otherwise fully recovered. As a consequence, HMV is required.

There are several advantages to HMV for patients. For example, HMV has been shown to improve clinical outcomes in terms of both survival and quality of life. A study by Downes and colleagues showed that HMV can reduce patient exposure to hospital-borne infections (Downes et al., 2007). It can also prolong survival (Marchese et al., 2008; Tagami et al., 2014). Furthermore, among amyotrophic lateral sclerosis patients, death after mechanical ventilation came later for patients at home than for those in the hospital (Dreyer, Lorenzen, Schou, & Felding, 2014). HMV also enhances the patient's health-related quality of life. Windisch's (2008) aimed a comparing and assessing the benefits associated with home mechanical ventilation (HMV) with health-related quality of life (HRQL) as the outcome variable. Both aspects of general and condition-specific health-related quality of life improved in patients one month and one year following initiation of HMV. Additionally, a systematic review of clinical outcomes related to HMV concluded that HMV increased health-related quality of life and reduced the need for hospitalization (MacIntyre et al., 2015). Similarly, another qualitative research by Ballangrud et al. (2009) on the experiences of patients living with HMV, found that having a home ventilator enhances quality of life and 'makes life worth living.' The ventilator treatment builds up strength and improves the well-being of dependent patients. Study participants also had felt it was significant to be in control of their own situation, and they had an overriding wish to live normal and active lives (Ballangrud et al., 2009).

Home also represents a safe, harmonious and desirable place for patients who depend on mechanical ventilation for the sustainment of life. In the home setting, patients enjoy everyday life with their families and friends (Lindahl et al., 2010). Patients have also reported having good relationships with others and satisfaction with their social lives and situations (Dyrstad et al., 2013). Consequently, being at home with mechanical ventilation helps prevent social isolation (Yamaguchi & Suzuki, 2013). Finally, another benefit of HMV is that it frees hospital ICU beds for critically-ill patients (Downes et al., 2007; Nava & Vitacca, 2013) and reduces the costs of institutional healthcare (Ballangrud et al., 2009; King, 2012). Therefore, HMV services act as a bridge to the home–based approach for continuous long-term care (Nava &Vitacca, 2013).

Global Policies Related to Care and Support for Patients on HMV

There are no global policy statements related to care and support for patients on HMV. Persons on HMV, however, are dependent persons who require care and support for long period, or as long as they are able to wean off it or pass away. Therefore, policies related to long-term care in both global and national level will be reviewed.

According to the WHO, LTC refers to the providing of services for persons of all ages who have long-term functional dependency. With an increasing aging population and an advancement of medical technology, the demand for long-term care (LTC) and service provision has been dramatically growing. Long-term care is provided in settings that range from the patient's home to community centers, supported living facilities at home, nursing homes, hospitals and other healthcare facilities. The scope and intensity of the providing care and support delivered can vary in any of these settings (Brodsky, Habib, & Hirschfeld, 2003). The WHO (2015) released the key policies issues in long-term care and suggested national health system to define the scope and extent of LTC must be accessible and affordable. Special consideration should be given to guaranteeing that marginalized and poor people can be access services. Key recommendations included:

1)LTC necessity encourage the human rights of people with dependency care. The care must be delivered in a way that improves dependent people's dignity and supports their self-expression, them be able to make choices.

2) LTC must improve dependent people's intrinsic capacities.

3) LTC should be person-centered. It might be focused on the dependent person's needs rather than the structure of the service.

4) The long-term care workforce, unpaid and paid, should be treated fairly in healthcare delivery, and it should obtain the social status and recognition it deserves.

5) National governments must take as a whole responsibility for the managing of long-term care systems.

National Policies for Long-Term Care

To date, Thailand has 12 National Health Development Plans and the focus of each plan is presented in Table 2.1. It was appeared that policies related to LTC first recognized in the Ninth National Health Development Plan (2002-2006); however, these policies lacked clarity and only mentioned the need to strengthen the primary healthcare level in order to link it with a higher level of healthcare services. In order to prepare for the country's aging population, the Tenth National Health Development Plan (2007-2011) focused on building a new health system to strengthen both communities and individuals. In the Eleventh National Health Development Plan 2011-2016, the fourth strategic health plan focuses on strengthening the healthcare system at all levels with quality and standards in response to the health needs of all age groups and with the aim of improving continuous referral systems in order to ensure good care during transportation and non-refusals.

Currently, the first strategy in the Twelfth National Health Development Plan (2017-2021) focuses on improving the efficiency of the public health service management system and enhancing the health financing system as follows: adjusting the medical equipment management system, setting up measures to manage health-related expenditures between the public area and patients, human resources, recognizing one's socio-economic status, access for low-income patients to necessary treatments, and improving the nation's public finance budget discipline.

Table 2.1

The National Health Development Plans and Focuses

National Health Development Plan	**Focuses**
1st-3rd (1961-1976)	• Efforts to make people healthy • Major health programs on family planning, maternal and child health, medical services, and communicable disease control for poor people
4th-5th (1977-1986)	• Adoption of a primary healthcare approach and decentralized management in the health sector to the local area, district, sub-district, and village levels
6th-8th (1987-2001)	• Managerial process for provincial health development • Importance of health information, health economics and healthcare financing in health planning
9th (2002-2006)	• Adopt a people-centered approach and the philosophy of a sufficient economy
10th (2007-2011)	• Advance health security and universal healthcare coverage
	• Practice disease investigation and inhibition for Thai and migrant labor and develop a new health system to further reinforce individuals and communities

Table 2.1

Continued

National Health Development Plan	**Focuses**
11th (2012-2016)	• Disseminate health resources appropriately with adequate medical and health personnel at all levels by using appropriate technologies; • Develop medical specialties to cover all localities as needed for people's convenient access to quality services; • Strengthen referral systems to ensure good care during transport and non-refusals; • Pay close attention to patient safety while receiving care that expands to the drug-dependency treatment services; • Create good care recipient-provider relationships and conflict resolution in cases of adverse treatment outcomes; • Promote good understanding between medical personnel and the public regarding treatment eligibility and expectations in order to ensure provider happiness and recipient satisfaction.
12th (2017-2021)	• Strengthen and realize the potential of human capital; • Create a just society and reduce inequality; • Strengthen the economy and underpin sustainable competitiveness; • Reinforce national security for the country's progress towards prosperity and sustainability. • Promote public administration, prevent corruption and promote good governance in Thai society;

Table 2.1

Continued

National Health Development Plan	**Focuses**
	• Promote advancing infrastructure and logistics; • Develop science, technology, research and innovation; • Enhance urban and economic zone development; • Promote international cooperation for development.

Although LTC policies have been launched since the Ninth National Health Development Plan, they have primarily focused on the elderly. Sasat and Pukdeeporm (2007) stated that one of the problems of LTC service in Thailand is the absence of institutional standard and competency requirements for the LTC provider. This problem brings about the question of quality of care and quality of life of such resident patients.

In term of healthcare financial expenditures, which involve a variety of home-based and institutional services, Thailand has three healthcare coverage schemes – the Universal Coverage Scheme (UCS), the Civil Servant Medical Benefit Scheme (CSMB), and the Social Security Scheme (SSS). These schemes cover all healthcare services such as treatment intervention, medicines, equipment-related and follow-up care for all registered nationals. Yet, all of these schemes fail to cover patients who stay at home and need LTC. The policies also exclude expenditures for medical technology equipment (Sakunphanit, 2015) such as ventilators, which are associated with high costs. Hence, families need to pay out-of-pocket in order to prolong the lives of their loved ones, while most of the people in the country are poor. As a result, the population's access to services is inequitable due to ineffective resource use and high health technology expenses.

Long-Term Care Services Related to Caring for Patient on HMV

In Thailand, the home care program provided to patients with invasive mechanical ventilation was initially developed with children at Ramathibodi hospital in Bangkok in 1995 (Preutthipan, 2000), whereas data on adult patients was not reported. According to the literature review by the researcher, the provision of care for adult patients with chronic respiratory failure who have difficulty weaning and are dependent on HMV has been available in clinical practice in Hat Yai hospital, Songkla province, Thailand since 2010. At Ramathibodi hospital, respiratory nurses take on the role of the home healthcare service provider with the main responsibility of training caregivers. Furthermore, nurses have to prepare all the necessary medical equipment and regularly visit the patient and family caregiver at home. After discharging of the patient from hospital to home, ambulatory nurses must contact the family by phone and then visit them at home one to two times a week. The nurse evaluates the abilities of the caregiver's skill, provide feedback to them, and discuss problems to the healthcare provider team (Preutthipan, 2000).

Recently, the healthcare team at Hat Yai hospital has started providing care to patients requiring HMV by means of a multidisciplinary team. Regarding the healthcare team, the nurse case manager takes on the management role. The family caregiver is trained to take care of their loved one at home by the nurse at the admission ward. Training and teaching the family caregivers is a very hard work for the reason that the family caregivers are not healthcare providers and they do not have any previous experiences and knowledge about dependent-patient with mechanical ventilation. After patient discharge, the home healthcare nurse and the nurse case manager regularly visit the patient and family at home. However, the healthcare team of Hat Yai hospital visits only HMV patients and families living in the area for which the hospital is responsible. The others need to contact the community hospital that is responsible for general providing care for them. A high incidence rate of readmission is found among such cases, especially in the first three months. However, some families are successful in providing care for their loved one who depends on mechanical ventilation at home without readmission.

As previously noted, the organization of the care services for patients on HMV at Ramathibodi and Hat Yai hospitals have some minor differences. They also share some similarities in terms of barriers for success in their work. One major problem for discharging HMV patient is the lack of accessible funding support. In Thailand, home care expenditures are not covered by governmental health schemes or private insurance. Families must meet the expenses of the medical equipment, caring supplies, and paid caregivers, yet, most of the people affected are of low economic status. The lack of support for families who provide care for their loved ones at home is another significant stumbling block.

As note previously, caring for patients on HMV is likely to be complex and require full-time support by the family caregiver, which makes it impossible for him/her to work outside the home. Consequentially, amounts of patients whose health conditions are proper for home care undertake medically unnecessary long-term hospitalization or suffer a high incidence of readmission. In order to succeed in caring for HMV patients, the challenges concerning not only resources, but also family caregivers and their ability to cope with the ensuing problems must be addressed.

Concept of Family Caregiving

Family caregiving is an integral part of a caregiver's life. Providing care for a dependent one with HMV is a dynamic process. Each entity has its own history, unique features and a path forward reflecting special circumstances of the family caregiver(s). Individual needs must be considered in the social context of the larger family. Consequently, understanding the family caregiving concept is importance and is later explained in this study: definition, characteristics, consequences, factors related to the family caregiving experience, Thai socio-cultural perspectives on family caregiving, and changes in the social and family structures within Thai society.

Definition of Family Caregiving and Family Caregiver

Family is a word that raises difference descriptions for difference persons. Depending on the disciplines, some definition focus on the specific aspects of family (Kaakinen, Gedaly-Duff, Coehlo, & Hanson, 2010). For instance, the legal description of family focus on relationships through blood ties, adoption, guardianship or marriage, whereas the definition of biological focuses on genetic biological networks among people. For sociologists define the family as a group of people living together, while psychologists explain it as a group with strong emotional ties (Hanson & Boyd, 1996). In addition, another definition of family was provided in the book titled "Family Health Care Nursing" indicated that two or more persons who depend on each other for physical, psycho-emotional, and economical support. The members of the family are self-defined. Family is further defined as an interpersonal system individual members view as family and includes the functional relationship between single individuals and others who are emotionally connected to individuals (Friedemann, 1995).

The terms *"caregiver"* and *"carer"* are used interchangeably and with similar meanings to refer to a person who provides appropriate care to a dependent. The Royal College of General Practitioners (RCGP) (2018) defines a carer as a person of any age who provides unpaid support to a child, partner, relative, or friend who is unable to manage living independently or whose well-being or health would worsen without this help. These carers are often described as lay, informal or family carers (Scottish Government, 2010). Recognizing the reality of modern family life, family caregivers are broadly defined. They can be not only relatives, but also friends, partners, neighbors, and others who manage or deliver the care for a person with a disability or serious illness (Levine, Halper, Peist, & Gould, 2010).

Moreover, the National Alliance for Caregiving & Emblem Health in US (2015) asserts that a family caregiver is somebody who is accountable for attendance to the daily living needs of another person. Careproviders are also accountable for providing physical, psycho-emotional and often economic support to another person who is incapable to care for him/herself because of illness, injury or disability. Similarly, O'Reilly, Connolly, Rosato, and Patterson (2008) defined family caregivers as individuals who provide unpaid care or help to people who are sick or in need of assistance with personal activities of daily living. Family caregiver is family member who provides some form of assistance to chronically ill or disable family member (Roth et al., 2013). Furthermore, a family caregiver can be described as having an informal relationship - a term professionals use to describe those who care for friends or family members in the home usually without pay or compensation (National Alliance for Caregiving & Emblem Health, 2015). The definition of an informal caregiver usually includes being a person who offers some type of unpaid work and on-going help with the activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a disability or chronically ill (Roth, Fredman & Haley, 2015).

The term caregiving can be defined as the performance of giving unpaid assistance care and support to a dependent person that has physical, psycho-emotional or developmental needs (Drentea, 2007). Hermanns and Mastel-Smith (2012) conducted a qualitative concept analysis and identified that caregiving is composed of individual who cannot do daily activities for herself/ himself. Similarly, Smith (1994), defined caregiving as "the provision of technical, physical and emotional care that results in outcomes of optimal patient quality of life and physical condition, minimal technological side effects for patients, and the maintenance of caregiver's health and quality of life." In addition, Pearlin et la. (1990) defined caregiving as the "behavioral expression of commitment to the well-being or protection of another person" (p. 583). The caregiving identifies not only as a role, but also involves actions within the context of a relationship (Pearlin et al., 1981). Therefore, family caregiving is the care delivered by a family care provider of suitable personal and health care for a loved one or another family member (Swanson et al., 1997).

Characteristics of Family Caregiving

Swanson et al. (1997) conducted study of concept analysis on family caregiving and defined a family caregiver as a family member who delivers appropriate personal care and health care for a family member, friends, or significant other. They conceptualized caregiving as taking the following four characteristics including caregiving tasks, caregiving transition, caregiving roles, and caregiving process.

Caregiving tasks refer to actions provided by family members that involve actions of daily living, both direct and indirect care, medical instrumental support activities of daily living, and the amount of care provided (Swanson et al., 1997). Both direct and indirect care are indicated. Direct care refers to the delivery of appropriate individual support and health care for a family member or significant other by a family caregiver. Furthermore, there are some basic indicators concerning the caregiver's completion of the activities essential to provide care for the care recipient. The family caregiver establishes daily routines to facilitate the care recipient's daily activities such as feeding, toileting, and bathing. Medical instrumental activities support of daily living such as ambulation, medication management, associated at doctor visits, and routine housework are also included. Moreover, indirect care is the coordination of appropriate care for a significant or family member other by a family caregiver. Providing comfort, safety, and attending to the care recipient's needs is also included in caregiving tasks (Swanson et al., 1997).

In addition, Milligan (2004) described caregiving tasks by four main categories: 1) physical care in the form of feeding, cutting nails, changing clothes, personalizing the patient's room and paying for treatment; 2) social care as in the case of visiting and entertainment, taking the patient for drives, acting as a channel to the social world outside residential care; 3) emotional care as in showing care, love and affection to the care recipient in ways not always explicitly spelled out by respondents, but demonstrated through other tasks; and 4) quality care as in monitoring the level of care, indicators of health, and standard of treatment as well as dealing with any problems that arise.

Secondly, *caregiving transition* is the perspective of family caregiving rather than performing tasks with the following important components: provision of care, performance of care activities, care management, delegation and management of activities, and the care transfer from a caregiving individual to an institution (Bowers, 1987; Pepin, 1992; Phillips, 1988). Changing of caregiving activities over time in a relatively predictable developmental progression in agreement with the care recipient. The need for care and the caregiver's role increase over time (Jeffs, 2017). Montgomery and Kosloski (1999) summarized the trajectory of caregiving with the following seven standards: 1) defining self as a caregiver; 2) performing caregiving tasks; 3) providing personal care; 4) finding or using assistance services; 5) the consideration of using an institution; 6) placing the care recipient in a nursing home; and 7) the ending of the caregiving role.

Thirdly, the *caregiving role is* defined as a common extension of the roles typically enacted by family members or significant others. Otherwise, mutual nurturing behaviors are an important part of caregiving. The following description provides support for the use of the averring of a caretaking role in which the needs of the person for physical and psycho-emotional support either are improved or ignored (Gitlin & Wolff, 2012). Schulz and Eden (2016) stated that the scopes of the caregiving role include the following: help with household chores, self-care activities, movement, providing of emotional and social support, medical and health care, advocacy and care management, and surrogacy.

Finally, *caregiving process* is another way to conceptualize caregiving. Bowers (1987) asserts that caregiving should be defined as a process, and proposed the following five conceptually distinct but empirically overlapping categories of caregiving roles including preventive, anticipatory, supervisory, and instrumental and protective. These categories implicate multiple tasks and role demands involved in caregiving, and emphasize the concept of caregiving as a process (Swanson et al., (1997).

Consequences of Family Caregiving

An important consequence to caregiving has a marked impact on the life of the family caregiver. Concerning impacts of caregiving on family caregivers of patients with chronic illness, family members have described both positive and negative experiences related to providing care for patients at home – psychological satisfaction and growth and emotional distress (Beach et al., 2000; Harmell et al., 2011). In addition, the negative effects of caregiving are commonly referred to as the ‘burden of caregiving’ (Ostwald et al., 2009). Therefore, both the negative consequences, such as the burden of family caregiving, and the positive consequences will be explained in this study.

Family Caregiving Burden.

The burden of family caregiving is often spoken of as perception of family caregiver about level of distress and demands such as responsibilities, tasks, and the pressure associated with caregiving roles (Gitlin et al., 2003). The most convincing evidence for burdensome caregiving is provided by the *physical health burden*, i.e. caregivers have low level of physical health outcomes when compared with various persons of non-caregivers (Gouin et al., 2012; Gupta et al., 2015; Lovell & Wetherell, 2011; Saban, Sherwood, DeVon, & Hynes, 2010). For example, caregivers are reported to experience nocturnal sleep disruptions and inconsistencies (Kotronoulas, Wengstrom, & Kearney, 2013; Pawl, Lee, Clark, & Sherwood, 2013) that puts them at a risk for poor physical health, and possibly leads to compromising their ability to continue in the caregiving role (Thomas, Saunders, Roland, & Paddison, 2015).

A second type of family caregiving burden is the *psychological burden* –caregivers describe a sense of duty to take care of their loved ones, but suffer a significant restriction of their own time with a negative impact on mental health (Gupta et al., 2015; Turcotte, 2013). A study by Brown and Brown (2014) emphasized that the family caregiving as a stressful assumption that a very narrow, simplified and limited view of these types of human relationships. Pierce and colleagues (2012) also pointed out that as the stress of caregiving becomes overwhelming, caregivers experience fear and hopelessness over the thought of another day of caregiving. They also share the overwhelming grief and frustration of watching the person with disability struggle and wish they could help provide adequate care (Nikora et al., 2004). Additionally, the caregiving stress may result in poor cognitive functioning that contributes to memory loss (Chen & Botticello, 2013) and increased mortality when compared to the non-caregiving population (Fredman et al., 2010; Roth et al., 2013).

Another characteristic is the *social burden.* An impact of the role of a caregiver is that it often isolates them. Caregivers report that the need to stay inside the house most of the time often leads to isolation and decreased leisure time. The literature review indicates that family caregivers disrupt their social activities and connectedness as their energy and time are attentive on their loved ones (Girgis, Lambert, Johnson, Waller, & Currow, 2013). Caregivers also frequently express that losing their social life is a serious lifestyle change (Girgis et al., 2013; Kang, Li, & Nolan, 2011). In the case of holidays, caregivers are unable to get away from home for vacations or visits with relatives, as they do not want to leave the safety of their home environment (Barnes et al., 2006). As a result, some caregivers become virtually isolated with limited social networks. Meanwhile, the presence of more restrictions in their daily activities is likely to lead to reports of increased caregiver burden.

Finally, the *financial burden* connotes that family caregiving creates a financial burden for family members, both in terms of financial costs and lost income (Girgis et al., 2013). Financial expenses as defined to direct monetary costs associated to paying for the caregiving expenditures, whereas others are linked to the loss of financial or monetary wages from service due to the need to achieve the caregiving role (Lai, 2012). Examples of the costs related to caregiving expenses are transportation, non- prescription medications, medical supplies, prescription medication, medical equipment, and household supplies (Lai, 2012). Not all the financial expenses can be measured by monetary value as some expenses are individually indicated to be concerned (Carmeli, 2014). Financial problems due to family caregivers suffering out- of- pocket expenses associated with their responsibilities are also present. For some, this financial commitment is inconsequential since it can have a significant impact on disposable income and personal savings (Girgis et al., 2013; Keating et al., 2013).

Positive Consequences of Caregiving.

Although many more studies have assessed the burdensome aspects of family caregiving, some also have highlighted its positive impacts. A recent study by the National Opinion Research Center (2014) revealed that many family caregivers reported positive experiences from caregiving, included the gratification of knowing that their loved one is getting good-quality care, a sense of providing back to someone who has given care for them, continuing their own individual growth and an improved purpose and meaning in one's own life. For some caregivers felt that they are getting through on a tradition of caregiving, and that, by caregiving model, their children will be more likely to care for them (National Opinion Research Center, 2014).

Additionally, becoming a family caregiver for someone who is significant to the family has many benefits and high value (Li & Loke, 2013; Rapanero, Bartu, & Lee, 2008; Tarlow et al., 2004). It is an honor and a rewarding experience. Family caregivers can create stronger bonds with the care recipients. They might even find this caring job pleasurable and a way of becoming a role model for the young generation in family. Another important aspect for family caregivers is that it provides their life meaning and becomes a source of pride in their success as caregivers (Li & Loke, 2013). Furthermore, they can provide back to someone else including the more one gives, the more one receives. When the family caregivers willingly provide of their energy, talents, skills, knowledge, time, or resources, they immediately set a standard of providing and grow into more responsive and sensitive to the wishes of others (Carmeli, 2014).

Factors Related to Family Caregiving Experiences

The issues associated to the positive aspects of family caregiving experiences included hope, social support and religious coping, personal characteristics and healthcare support.

Hope - Family caregivers often report holding on to several hopes during their caregiving process as follows: a natural remission of the disease or the hope of a miracle cure; the hope of operational pain control and symptom management and the hope of receiving good care and support from health professionals, friends and communities (Clayton, Butow, Arnold, & Tattersall, 2005). Hope helps them adjust and cope well with caregiving situation. At what time discussing the prognosis of patient and end-of-life issues with healthcare providers, family caregivers also frequently express their belief that there are ways to foster coping and nurture hope. Clayton et al. (2005) also stated that hopeful for the best whereas preparing for the worst is one of the strategies for coping in clinical practice. Interviews from one qualitative study revealed that hope was something potentially meaningful to anticipate in the future (Milberg & Strang, 2003). This was corresponding with the results of another study illuminating that hope is the continuing process of building self-confidence and regaining inner strength to make sense of one's situation (Holtslander & Duggleby, 2009). Through hope, family caregivers learn to stay positive and move on with their lives.

Social support and religious coping - Several studies have reported that social support and religious coping have optimistic effects on family care providing. One study has described that family caregivers with a religious association and caregivers who perceived greater support from family are more possible to positive caregiving experience (Kang et al., 2013). In addition, one study has suggested that social support and religious coping are linked to greater positive effects on caregiving outcomes (Fitzell & Pakenham, 2010). Conversely, the study presence of negative religious coping has been found to be associated with a poorer quality of life and lower satisfaction (Pearce, Singer, & Prigerson, 2006).

Personal characteristics - Personal characteristics as a self-esteem of family caregivers (Kim, Baker, & Spillers, 2007), gender and motives (Kim, Carver, Deci, & Kasser, 2008), which are also found to be correlated with the family caregivers' well-being. Another study has shown that family caregivers with a greater level of self-esteem report lower psychological distress and better mental functioning and spiritual adjustment (Kim et al., 2007). Regarding gender and motives, it was found that male spousal caregivers rated higher level of external caregiving motives than females. On the other hand, women caregiver reported finding more benefits from the caregiving process than did men caregiver (Kim et al., 2008).

Healthcare support - Informational and emotional *s*upport from healthcare professionals are recognized as essential elements benefitting individuals involved in the caregiving process (Sano et al., 2007; Tang, 2009). The family caregivers reported having done their best in terms of giving care at home in that the patient was capable to live at home until the end of their life with assistance from a healthcare care service (Sano et al., 2007).

Thai Socio-Cultural Perspectives on Family Caregiving

Thai family caregiving experiences for dependent persons is socially and culturally constructed. In this section, the social structure and cultural context of the Thai family are discussed to offer a consideration of the family caregiving process in Thailand. It was appeared that hierarchy relationships, traditional gender roles and Buddhist beliefs remained vital to describe understanding of Thai family behaviors (Pinyuchon & Gray, 1997).

Hierarchy relationships. The hierarchy relationship is important in the Thai social and family structure and related to the role of providing care for sick family members, in particular. The hierarchy relationship is determined by age, knowledge level, position of power and occupation (Smith, 1979). In addition, the hierarchical structure describes sets of duties and responsibilities and specifies appropriate behavior in the family (Pinyuchon & Gray, 1997). In the past, the family structure was linear and organized in accordance with four principles including formal authority going to men, juniors paying respect to seniors, seniors assuming responsibility for the juniors' well-being (Potter, 1977). Reports in Thai rural families have also revealed that the father leaders and protectors while the mother plays a supportive role such as handling finances and influencing family decisions (Smith, 1979). The children are expected to be appreciative and respect their parents (Bumroongsook, 1995). Predominantly, daughters or daughters-in-law are also expected to provide care for their parents or ill family members (Ritteeveerakul, 2005; Sasat et al., 2000).

Traditional gender roles. Additional importance is given to the cultural aspects manipulating the Thai family caregiving based on traditional male and female gender roles. According to ancient Thai culture, the male role can be compared to the front legs of an elephant, while the female role is related to the hind legs (Warren, Black & Rangsit, 1988). This means that a Thai traditional woman is required to show respect to her husband. In the past, the Thai culture placed husbands as leaders of the family, taking care of his wife and children, while wives were responsible for attending to her husband's needs, instructing the children and doing housework and not allowed to decide anything without the husband's consent (Pinyuchon& Gray, 1997). Nowadays, however, women have more rights to mad decisions about their lives. Although decidedly archaic, this culture continues to influence female gender roles in Thailand, particularly among mothers and daughters, who play a major role as primary caregivers in their families (Yoddumnem-Attig & Attig, 1993).

Religious beliefs. Religious beliefs have tremendous influence over the daily living of Thai people. The majority of Thai people are Buddhists who believe that one's life does not start with birth and end with death (Pinyuchon & Gray, 1997). Each life is conditioned by volitional performances (Karma) committed in previous existence. The view of karma is defined in terms of the law of cause and effect (Pranke, 2011). Persons who perform good performances will receive good consequences, and those who perform bad acts will experience negative events in their lives. This might not appear in one's present lifetime, but may emerge anytime in one's cycle of births and deaths. Belief in Karma is very influential and affects Thai values, attitudes and behavioral patterns toward life (Pinyuchon & Gray, 1997), particularly the role of providing care for family relatives who are ill at home.

Changing Social and Family Structures in Thai Society

According to The Ministry of Social Development and Human Security, Thai families are classified into the following three types (UN Statistics Division, 2015): 1) extended families or three-generation families including parents, children and grandparents; 2) nuclear families composed of one generation with a husband and a wife, and two-generation families composed of parents and children; and 3) special needs families including those with a specific composition or those with special needs, for example skipped-generation families with elderly people looking after the children with no working-age adults (parents) or single-parent families with only a father or a mother and a child/children. With Thai families in 2015 existing in an era of low fertility and longevity (UNFPA, 2015), the effects of modernization and globalization have led Thailand into a number of new directions: the transition from middle-income to high-income lower income to middle income the exodus from rural to urban living, and the transition from a larger family size and a shorter life expectation to an aging population with a lower birth rate. All these social and economic transitions are inter-connected which influence and impact the direction of family life.

Family types and living arrangements are also changing. In the past, the extended family structure usually found in Thai society was composed of parents and children as well as grandparents, aunts, cousins, a married daughter or son, his or her spouse and possibly their offspring, all of whom live in the same house (Richter & Podhisita, 1992). At present, the number of nuclear families in both rural and urban areas has dramatically increased over the last several years. In accordance, the family size in Thai society has decreased over the last decade (Peek et al., 2016).

Due to the change of the family structure from extended to nuclear, both men and women have to work outside their home to provide financial support for the family (Knodel & Chayovan, 2009). Consequently, family resources and their ability to provide care for relatives who need support are limited (Limanonda, 1995). Families tend to require more supporting services from communities in order to take care of their loved ones and relieve their burden (Chunharas, 2007). Therefore, family caregivers face numerous and serious challenges. They experience the burden of both working outside of the home and providing care for their loved one. In some case, caregivers may manage their responsibilities by employing someone or asking other family members to help provide care at home.

Family Caregiving for Patients Dependent on HMV

Successful HMV is associated with the experiences of both the patients and their family caregivers. This section will describe the patient’s perspective on demand from family caregivers, the family caregiver experience and nursing care to promote family caregiving in HMV-dependent patients.

Caregiving Demands in Patients with HMV

Although HMV improve positive clinical outcomes and quality of life, continuous care at home with mechanical ventilation is challenging. Patients with technological dependent have high and complex care demands. Respiratory assistance devices and tracheostomy care are usually considered life support; the loss of this support would result in serious harm or death. Most of the patients utilizing such devices are at a high risk for sudden death and frequently die from respiratory causes (Sancho, Servera, Daz, Banuls, & Mar, 2011). Dreyer et al. (2010) reported the experiences of patients with physical impairment and HMV. They found that studied participants shared some life-threatening events such as the ventilator tube becoming disconnected, a malfunctioning alarm or being unheard by anybody, which resulted in not receiving air from the ventilator. Therefore, patients requiring invasive mechanical ventilation at home face significant challenges due to the complexity and difficulty of family caregiving (Huang & Peng, 2010).

Apart from physical and technological care demands, patients on HMV also require psychosocial care from their caregiver. Tsay and colleagues (2013) conducted a meta-synthesis study, aiming to describe the nature of the experiences of adult ventilated patients. They found that sense of fear because of dependence on a mechanical ventilation and loss of control of life was one main concern among patients with HMV. Also these patients encountered several struggles such as feeling regretted the fact that life has changed for the worse and uncertainty in their illness and future (Dyrstad et al., 2013; Fex et al., 2011). Moreover, patients receiving HMV encounter an unnecessarily long and lonely struggle to achieve effective communication (Laakso, Markstromt, Idvalls, Havstamt, & Hartelius, 2011; MacIntyre, 2012). They have trouble with their speech and voice production (Laakso et al., 2011). They felt disconnected with the world surrounding them and loss of self (Tsay et al., 2013). Apparently, these patients with HMV voiced their needs for support from healthcare professionals and family (Dyrstad et al., 2013).

Family Caregiving Process and Experience with Patients on HMV

In order to gain better understanding about current situations of family caregiving experiences related to home ventilator-dependent patients, a review literature was systematically conducted. The databases searched were the PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), OVID, Google Scholar, Science Direct, ProQuest Nursing, and Pacific Rim International Journal of Nursing Research. The search included all English language literature published from

2000 to 2015. The key terms used were as follows: caregiving, process, outcome, home mechanical ventilation and ventilator-dependent patients. The primary search found 1,168 articles. Of these, 156 studies were considered for abstract or full-text reviews; 132 studies were excluded due to irrelevant content and/or relation to the pediatric population. Eventually, 24 studies were included in the review. Key findings from the review can be categorized five issues, as outlined below:

Family caregiving adaptation **-** Huang and Peng (2010) explored the adaptation roles of family caregivers for ventilated patients after transfer from hospital, a respiratory care unit to home. This Hong Kong study found that the family caregiver's transition to the role of caregiving is a dynamic process with consequences that are impacted by the level of the family support, affective rewards from the patient, the patient's health condition, and a balanced life for the family caregiver. A subsequent study by Dybwik et al. (2011b) explored the experiences of families providing advanced care for family members dependent on HMV. The findings identified "fighting the system" as the core category of the family caregiving process. Three subcategories, "lack of competence and continuity", "being indispensable" and "worth fighting for" were present. Additionally, this study also pointed out the need for further study in this population, especially in regards to family caregiver expectations and the community healthcare services provided for this population. There is a larger need for future study from perspective of a family nursing as well as from each family member. Additionally, a study by Briscoe (2008) on the caring experiences of patients with HMV in sustaining the patients' families discovered the following five themes that characterize the essence of the caring for patients with HMV: (1) intrusion of symptoms; (2) being there; (3) bridging two worlds; (4) making peace with the ventilator and (5) life goes on with new vigilance (Briscoe, 2008). In addition, a study by Scott and Arslanian-Engoren (2005) investigating the challenges and choices of family caregivers of prolonged mechanical ventilation patient found that this requires a lifestyle change to their situation.

Family caregiving collaboration **-** The family caregiver roles and the healthcare providers' collaboration are a challenge in community healthcare services for HMV patient dependent on highly advanced technology and continual care. The study of Dybwik et al. (2011b) evaluated the collaboration family caregiver roles and healthcare professionals. According to the findings, both groups should have more discussion concerning appropriateness desires, privileges and limitations of patients in the delivery care and use of ventilation support in private homes in order to discovery solutions to enhance their collaboration.

Family caregiving communication **-** A study on the communication between a partner and the individual receiving HMV identified difficulties and limitations in communication (Laakso et al., 2014). Moreover, the skills caregivers' need to learn and adopt a variety of strategies, and their role in supporting individuals receiving HMV help enhance and empower communication between patients and family caregivers.

Family caregiving contributing factors **-** According to study of Rose and her colleagues (2015) in a survey on a web link from August 2012 to April 2013, competence of caregiver is a requirement for discharging from hospital to home. Significant barriers to the home transition included the following: insufficient funding for medical equipment and supplies; paid caregivers; a shortage of paid caregivers; and poor negotiations for public funding arrangements (Rose et al., 2015). Therefore, caregiver availability is an important barrier to home transition. Additionally, caregiver attitudes and lack of advance planning influence tracheostomy invasive ventilator (TIV) utilization (Rabkin et al., 2014). Similarly, a study in Amyotrophic Lateral Sclerosis (ALS) patients who were dependent on HMV concluded that the skills of the family caregivers can help patients to have activities outside the home (Mizuno, Ogura, & Kawamura, 2004). Moreover, trust and confidence in family caregivers are also important to patient's dependent on HMV when the patient is provided the chance to involved in decision-making about care and treatment such as where to live and how to organize daily life (Dyrstad et al., 2013).

Family caregiving burden **-** Patients who choose home ventilation report a high level of burden to family caregivers. The results of a study on HMV-dependent patients that aimed to describe the impact of the situation on caregivers suggest that most of the caregivers are either overburdened or at risk for becoming overburdened (Fernandez-Alvarez et al., 2009). Consistently, higher levels of burden are found in caregivers of tracheostomy-ventilated patients compared to caregivers of non-tracheostomy patients (Kaub-Wittemer, Steinbuchel, Wasner, Laier-Groeneveld & Borasio, 2003; Marchese et al., 2008; Van Kesteren, Velthuis, & Van Leyden, 2001). Additionally, a study by Evans et al. (2012), which was a mixed-method design with semi-structured caregiver interviews, pointed out that the Caregiver Burden Inventory scores supported a high level of burden in relation to a sense of duty, restrictions on day-to-day life, physical and emotional burdens (Evans et al., 2012). Furthermore, a regression analysis presented that daily functioning of patients, depressive symptoms of caregivers and the availability of family support had independent associations to the caregiving burden which might explain the 45-percent variance (Tang et al., 2011).

Moreover, three caregiver outcomes included: lifestyle disruption, employment reduction and depression risk) were also reported. The prevalence of the caregiver's depression risk was at an all-time high and did not differ by the patient's pre-ICU health conditions. Lifestyle distraction and employment reduction were also common and persistent (Van Pelt et al., 2007).

Ethical challenges **-** When one considers HMV ethics, this issue presents a challenge and is difficult to evaluate the considerations of the patient against the attentions of the family, the healthcare profession or society at large. Deciding who should be provided home ventilated patient, respect for patient and family wishes, dignity, equal access to HMV and other medical instruments, and quality of life are important and frequent challenges (Dybwik et al., 2011a). Moreover, in patients who diagnosed with amyotrophic lateral sclerosis, adequate physician description and nursing advocacy for autonomous patient decision-making were identified as critical for improving hope in regards to invasive mechanical ventilation, decision-making factors and psychological conflicts (Hirano & Yamazaki, 2010). Finally, withdrawing mechanical ventilation is related to legal issues because the decision to turn off mechanical support signifies terminating the patient's life (Geiseler, Karg, Borger, Becker, & Zimolong, 2010). However, withdrawal of mechanical ventilation is not a common practice, and the approach to this issue is highly variable, depending on the clinical scenario (Paruk et al., 2014). Le Bon, and Fisher (2011) have suggested that the impacts of the provision of this treatment and its withdrawal on caregivers, community trust managers, the primary healthcare team, and specialist palliative care teams should be discussed.

Nursing Interventions to Promote Family Caregiving

A comprehensive search was undertaken by using computers and electronic databases involving all English language literature published from 1995 to 2015. Articles were retrieved from the PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), ProQuest Nursing Science Direct, and Pacific Rim International Journal of Nursing Research. The key terms used were existing home mechanical ventilation program, education and supportive care program, clinical practice guideline invasive home mechanical ventilation, ventilator-dependent patient, and long-term home mechanical ventilation intervention.

A total of 42 articles were found and retrieved from the PubMed database. After reading the abstracts of the articles, only one article was found to be related to this study. From the 104 articles that were found using the ProQuest Nursing database, only one article was relevant to this study. The search using the Science Direct database yielded 33 articles, but none were related to this study. From CINAHL, 97 articles were found, but five studies were relevant, whereas the search of the Pacific Rim International Journal of Nursing Research yielded no publications related to this study. The details on the articles found are described in Table 2.2.

Table 2.2

Number of Articles Found in Electronic Databases

Electronic Database	**Articles found**	**Articles related to intervention**
PubMed	42	1
ProQuest Nursing database	104	1
Science Direct	33	None
CINAHL	97	5
Pacific Rim International Journal of Nursing Research	None	None
Total	**276**	**7**

According to the review, seven existing intervention programs regarding the improvement of caregiving and outcomes of using HMV among patients were identified. Four programs involved clinical practice guidelines and documents for discharge planning from hospital to home in order to improve patient and family outcomes. These were ‘Clinical Practice Guideline’ (McKim et al., 2011), ‘Clinical Pathway of the Discharge-coordinator Program’ (Tearl, Cox, & Hertzog, 2006), ‘PDCA Discharge Planning Program’ (Warren et al., 2004), and ‘Using Guidance Documents for Criteria of HMV: Process of Preparation and Activities at Discharge for HMV’(Glass, Grap, & Battle, 1999). Meanwhile, a study – Teaching and Learning Plan Program for the Parents of Infants with Tracheostomy (Joseph, 2011), focused on teaching family caregiver activities provided to loved ones. Kendig, Nonaillada, Ramaker, and Samuels (2008) proposed a respiratory rehabilitation program consisting of deep breathing exercises, limb strengthening, reconditioning, functional training and early mobilization in order to improve patient functional status. Additionally, the

Ontario Telemedicine Network (OTN) technology program (Watling, Kohli, Goldstein, & Avendano, 2014) utilized personal computer video conferencing service under the telephone assistance of a pulmonologist and nurse. Another study involved the monitoring of the patient's pulsed arterial saturation, heart rate (HR), breathing pattern tracing for weaning from mechanical ventilation through the use of remote monitoring at home via a tele-pneumology program (Vitacca et al., 2007).

As patients with breathing impairments requiring mechanical ventilation are typically cared for in ICUs (intensive care units) or, when available, in specialized weaning clinics for prolonged care or preparations for discharge to home (Navalesi et al., 2014). Family caregiving for such patients at home is associated with a particularly heavy workload as caregivers need to take on the responsibilities of long-term and around-the-clock care. The patients in need of 24-hour home care often have conditions requiring several medical procedures daily, and these are normally performed by healthcare professionals. Examples are administration of medication, parenteral nutrition, tracheostomy care and handling of technology (Bystedt et al., 2011). Additionally, that the offering of individualized support is also considered a moral obligation that reports each exclusive family-life situation. The way in which caregivers show their willingness and competence to become elaborate in the family's safety and problem solving are of significance for well-being of the whole family (Lindahl & Lindblad, 2011). The attitudes and circumstances of ventilator users and the quality of their relationships with their loved ones can make a significant difference in the ability and willingness of family members or significant others to take on the responsibilities of long-term, round-the-clock care (Cazzolli, 2008). Family caregiver perspectives may also directly affect their loved ones' need to live or die and the decisions they make.

Therefore, there is a significant need for knowledge in this area in Thailand. Particularly, a deeper appreciation of the family caregiving process aimed at not only understanding the issue, but also assisting healthcare professionals in developing better care for both patients and their families. Furthermore, the rationale for considering the family caregivers' attitudes about family caregiving and how they deal with day-to-day problems in their effort to balance between the caregiving demands of the patient and the family daily functioning. These are factors that play an essential role in the caregiving process for ventilator-dependent loved ones.

Grounded Theory Methodology

Glaser (1978) stated that Grounded theory is a qualitative research methodology. The goal is to generate a theory that explains patterns of behavior that are relevant and problematic. This theory was exposed, developed and verified through systematic data collection and analysis (Glaser and Strauss, 1967; Glaser, 1992; Strauss and Corbin, 1990, 1998). According to Benoliel (1996), a grounded theory study is founded on the assumption that both people and knowledge are dynamic, and that the context facilitates influences or hinders human aims, and the socio-psychological processes. Most grounded theories define the basic social processes which represent "theoretical reflections and summarizations of the patterned, systematic regularity movements of social life people go through and which can be conceptually captured and further understood through the construction of basic social process theories" (Glaser, 1978, p. 100).

Grounded theory contains a set of tentative hypotheses about a problem. Meanwhile, it uses the experiences of actual people confronting problems. Furthermore, grounded theory can be modified as changes in problems, situations and people. This flexibility is unique to the grounded theory methodology. It allows theories to develop as newer facts emerge, creating dynamic tools that remain beneficial over time and continue to be appropriate, even when situations change (Nathaniel & Andrews, 2007).

Moreover, Morse (2001) explained the grounded theory is an inductive process of data collection that the researcher has no fixed ideas to demonstrate. Relatively, issues of significance emerge from the participant's experience. The researcher analyzes data through constant comparison; initially from data with information from the participant, developing to comparisons between categories and codes and more data (Strauss, 1987; Strauss & Corbin, 1998). This constant comparison is provided as the basis for the researcher's final theorizing of the participants' experiences (Corbin & Strauss, 2008) dependent on the researcher's point of truth and reality. Nevertheless, to confirm a strong research design, a philosophy that is consistent with the researcher's beliefs about the nature of reality is appropriate (Glaser, 1978).

History

Grounded theory is a qualitative research methodology was first applied by two sociologists, Anselm Strauss and Barney Glaser. Strauss, with a strong knowledge about qualitative research and symbolic interactionism from the University of Chicago, while Glaser had completed a PhD program at Columbia University in New York, and his training was in quantitative methodology (Strauss & Corbin, 1990).

Later, while conducting qualitative analysis, Glaser recognized the essential need for a well-supposed, clearly framed and systematic set of procedures for both coding and testing hypotheses generated during the research process. At the time, both the Columbia and Chicago research traditions were directed toward generating research that would be used by professionals (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

Consequently, the grounded theory developed from Glaser and Strauss' collaboration in a study to examine the experience of dying led to the publication of their book '*Awareness of Dying*'. Then '*The discovery of grounded theory*' was published in 1967 as the first publication that offered a rationale tree for a theory developed and generated through interplay with the data collected during research projects in order to suggest the logic specific to the grounded theory, and legitimate careful qualitative research (Charmaz, 2000; Strauss & Corbin, 1994).

Evolution

Throughout the years, grounded theory as a research design has become gradually popular, possibly in concurrence with the increasing number of books and papers using this methodology. However, there are some different viewpoints between the two co-originators, Glaser and Strauss, as the publication of Strauss and Corbin's '*Basics of Qualitative Research: Grounded Theory Procedures and Techniques*' in 1990 indicated. The two different points become apparent when examining the study. The first one is concerned with some relevant background information on grounded theory. According to Glaser (1992), ontologically, the traditional grounded theory can be deemed a post-positivist theory based on the evidence of critical realism. In addition, traditional grounded theorists believe that there is a real reality, but that this reality can only be imperfectly perceived (Charmaz, 2000). Meanwhile, Strauss and Corbin (1990) emphasized the importance of identifying structure, the applicability of which to explicit philosophical points of view like symbolic interactionism, and a confident large of flexibility and openness are essential to be able to adapt the procedures to different phenomena and research situations (Strauss & Corbin, 1990).

The second difference is concerned with the analysis processes and the explicit procedures used to regard the different stages of data analysis particularly focusing the issues of coding, emergence versus forcing and verification the researcher involves with the data (Walker & Myrick, 2006). Conversely, differences are found in the interventions and activities the researcher involves with the data.

Over the years, after the publication of *'Discovery of Grounded Theory*,' qualitative American sociologists have shown a great appreciation for the more explicit and systematic conceptualization that establishes theory (Strauss & Corbin, 1994). Several researchers have adopted with a variety of the ontological and epistemological positions to grounded theory methodology. At the time of the conception grounded theory, constructivist thinking was becoming very influential. Charmaz initiated to publish articles on the constructivist grounded theory (Charmaz, 1995) focused on the interactive relationship between the participants and researcher in the research process. Consequently, Charmaz brought the researcher centrality into the methodological principal and the importance of writing an ending text that keeps grounded in the data (Charmaz, 2000; 2006). Furthermore, it provides the reader with a feeling of the analytical lenses through which the researcher looks at the data (Bryant & Charmaz, 2007).

In addition, other philosophies have been applied to the grounded theory methodology such as critical thinking (MacDonald, 2001), feminism (Wuest & Merritt, 2001) and post-modernism (MacDonald, 2001). We can view the methodology of grounded theory as a spiral that starts with the traditional form where the following adaptations are insightful of the several moments of philosophical beliefs that guide qualitative research (Lincoin & Denzin, 2000), and ontological and epistemological position of the researcher determines the form of grounded theory undertaken (Annells, 1997).

Methodologically, there is no right or wrong approach to using grounded theory methods in qualitative research (McCann & Clark, 2003). However, there are differences that are essential to the explanation of the importance of grounded theory methods. Consequently, the specific uses and views of grounded theory have been either directly or indirectly influenced in terms of thinking through the different traditions and importance of alternative analysis models (Strauss & Corbin, 1994).

Philosophy

Grounded theory developed as a theory from successive conceptual analyses of empirical resources, following the grounded theorist’s belief that there is a socially constructed reality, and that truth emerges from interpretation and analysis (Strauss & Corbin, 1998). Strauss (1987) suggested that theory must be grounded in the reality of life experiences. Therefore, grounded theory was developed with the inspiration of philosophical and sociological paradigms of American Pragmatism and Symbolic Interactionism (Corbin & Strauss, 2008; Glaser & Strauss, 1967).

Pragmatism - Grounded theory method is linked to the pragmatism of John Dewey, William James, Margaret Mead and Charles Peirce. Moreover, neo-pragmatists Rechard Rorty, Jurgen Habermas and Cornel West extended the classic principle, endorsing a thoroughly interpretive, hermeneutic pragmatism. As a philosophical view of communication, interpretation and problem investigation, pragmatism was first developed in the 1870s by Charles Sanders Peirce (Rorty, 1982). Peirce pointed out that a human being is connected to a specific action that leads to a defined outcome. For the pragmatist, therefore, truth and meaning are the consequences of a purposeful action (Peirce, 1878). Denzin and Lincoln (2013) stated that pragmatism focuses not only on the consequences and meaning of an event or action in a social situation, but goes far beyond given the fact that the researcher studies, reflects, and inspects on an action and its consequences. Moreover, Peirce (1878) regarded pragmatism as a technique for problem solving that focuses on the method and process of interpreting the meanings of words, ideas, signs, and concepts with the aims of facilitating communication and judging their value by their functional consequences.

Later, William James further redefined pragmatism and developed it as a theory of truth, stating that it is a beneficial leading thought that guides people through experience in ways that provide consistency, pattern and predictability (Rorty, 1982). On the other hand, truth is the ability to think clearly with a purpose for positive social value (James, Bowers, &Skrupskelis, 1975). Based on the concepts of Peirce and James, John Dewey reformulated pragmatism into what he called "instrumentalism" (Rorty, 1982, p. 172). Dewey's instrumentalism states that the mind consists of cognition in establishing ideal instruments to cope with a specific situation, identify purposes and direct future outcomes (Eldridge, 1998).

In addition, pragmatist philosophies have been used to inform the philosophical epistemology of symbolic interactionism, which is also rooted in the grounded theory methodology. Blumer (1969) developed the symbolic interaction approach based on the work of George Herbert Mead, who maintained that meaning is created by symbols for concepts through interactions. It is a researcher's objective to discover the symbolic meanings, situations, signs, objects and words people have in order to interact within their life group (Cutcliffe, 2000). Additionally, Chenitz and Swanson (1985) noted that symbolic interactionism is important in helping to conceptualize behavior in complicated situations. Furthermore, it is very useful for healthcare personnel when the interaction with the healthcare system is a factor affecting the way patients manage their healthcare problems.

Symbolic interactionism - Symbolic interactionism is a theory of human action and a way to study the human group life from a sociological viewpoint (Strauss, 1987). This approach was mainly derived from the aim to understand social processes, interactions and changes. Symbolic interactionism views any human society as groups of human beings who are attractive in actions with a continuing process of suitability together the activities of its members. There are three fundamental assumptions of symbolic interactionism. First is the meaning that things, either physical or abstract, affect the way individuals act toward them. Second is the meaning that things are the results of the social interactions the individual has with others. Lastly, each person makes and modifies meanings through interpretative processes when dealing with such things (Blumer, 1969).

The way humans interpret things as initiating from the interaction process among humans are regarded by symbolic interactionists. The meaning of things is not only an intrinsic makeup or personal psychological expression, but it is also the fact that humans mention to themselves the things that have meaning for them through a process of self-interaction in which one communicates with oneself, and an individual interacts with others in order to assign meanings to things (Blumer, 1969). These meanings set the way that physical, social, or abstract objects are discussed, acted toward and perceived (Berger & Luckmann, 1967). Since meaning is created through the self by the discovery of new experiences, the individual creates new self-definitions and changes behavior (Chenitz & Swanson, 1985).

Since human society is a life group, shared meanings toward objects, actions or situations are the results of group interactions through communication and group consensus (Chenitz & Swanson, 1985). Individuals learn shared meanings and act in ways that are appropriate to the group because their behavior has meaning in the group. Shared meaning creates a collective behavior toward relevant phenomena and people. The degree of shared meaning can be influenced during the interaction process when humans bring a set of values and beliefs into that interaction (Jezewski, 1995).

Stemming from the idealism tradition, which holds that reality exists only in the form of how individuals view the world or through the human experience of daily living, symbolic interactionists believe that human beings indicate or refer to things as viewed from their perspectives (Blumer, 1969, p. 27). Based on this point of view, it is necessary for researchers who employ symbolic interactionism methods to explore the situation from the actor's perception, investigate what the actors take into account in a given situation, and describe how the actor interprets that situation, which results in particular actions. Chenitz and Swanson (1985) suggested that, in order to achieve this, the researcher must take on the role of the other by being both a participant and a bystander in the world. It is in this way that researchers can come to know about their inquiry, i.e., by having their data and interpretation emerge from and remain grounded in the empirical life of the people under study (Denzin, 1992). The tenet of symbolic interactionism to seek explanatory theories that are interpreted, grounded and emergent from the data has contributed profoundly to the methodology of grounded theory.

Based on the perspectives of those trained in the symbolic interactionist tradition, it should come as no surprise that one manner of thinking about sociology as the study of people performance somethings together (Becker, 1986). Grounded theories study as initially considered are focused on towards micro-level processes reflected in both action and interaction. The researcher focused on the study of patterns of behavior and meaning, which accounted for interactive variations around a substantive problem to reach at theoretically based explanations for the processes operating within the substantive problem area.

Other Qualitative Methodologies

The aims of this study are to describe the process family caregivers follow to move forward and harmonize their caregiving role for HMV patients with daily life. The process of the acceptance of the caregiver role, providing human care for loved ones and interactions among caregivers, family members and individuals in society are the multidimensional aspects of caregiving and coping regulations. However, in order to explore the caregiving phenomena related to the ventilation of patients at home, studies need to be characterized by a naturalistic perspective and interpretation derived from the research methodology. The following three alternative designs and methodologies with potential for use in studying this topic of interest were identified: phenomenology, ethnography, and grounded theory.

In phenomenology, truth is understood through person experiences. By close consideration of individual experiences, the phenomenological analyst looks for to capture the common features and meaning of an experience or event (Holloway & Galvin, 2017). As an abstract entity, the truth of an event is subjective and understandable only through in person perception. Hence, the researcher creates meaning through the experience of moving on space and across time. The phenomenological viewpoint is nicely focused in a remark attributed to express the differences between chronological time and embodied time (Balls, 2009). While, ethnography is a qualitative form of naturalistic examination that has a specific interest in cultural context (Holloway & Galvin, 2017). Regarding to Atkinson (1992), the word ethnography literally means 'the writing of culture.' The purpose of ethnographical research is to view the world through the eyes of the members of that culture under examination (Barnes, 1996) and to capture the social interactions among those members who participated (Arnould & Wallendorf, 1994). That includes accounting for information learned by such members to enable interactions, and studying the ways in which behaviors are subsequently organized (Holloway & Galvin, 2017).

As a result, the phenomenological approach only focuses on describing human life experiences and their meaning (Holstein & Gubrium, 1998) it cannot represent the process of interaction between people. The ethnographical approach focuses on describing culture-specific groups of people or describing a phenomenon associated with a cultural group (Morse, 1992). Although the ethnographical method can provide descriptions of the patterns of human behavior and the structure in a culture, it cannot explain the social process of human interaction (Cutcliffe, 2000).

In a grounded theory study, explaining is representing or telling a story that very graphic and detailed method, while stepping back and forth to interpret events or explain why certain events occurred and others did not occur (Corbin & Strauss, 2008, 2015; Strauss & Corbin, 1998). Moreover, categorizing events and objects involve explicitly stating dimensions and relating categorizations to one another to form an overarching explanatory scheme. Meanwhile, theorizing is the acts of constructing from data with an explanatory scheme that systematically integrates various concepts through a statement of relationships. A theory does more than just paint or provide understanding an intense picture. It enables users to describe and predict events, thereby, providing guides to action (Strauss & Corbin, 1998). Moreover, Morse (2001) contends that the grounded theory methodology is predominantly beneficial in discovering phenomena of which little is known. Therefore, it is a flexible means of inquiring definitely in terms of data collection and analysis. The phenomenon of spontaneous humor in healthcare interactions is a reasonably unexplored area, and, therefore, data collection and analysis need to be responsive and flexible.

Furthermore, the steps of open coding, axial coding and selective coding performed in constant comparison fashion and theoretical sampling allow the researcher to collect and analyze data systematically, while also enabling him/her to look for relevant concepts (Strauss & Corbin, 1998). Consequently, researchers can check, refine and develop ideas and intuitions about the findings as the data is collected. Moreover, the theoretical sampling feature allows the researcher to collect data from other sites, persons and contexts that are relevant to the emerging concept, thereby leading to the discovery of influencing factors (concept indicators) and a pathway or process (Strauss & Corbin, 1990). The systematic nature of the method is useful in judging, generalizing and comparing the results of a grounded theory study.

Grounded Theory in Nursing

Grounded theory study was used in nursing to discover complex social phenomena or importance phenomena for which there is rare or no theory report (Glaser & Strauss, 1967; Field & Morse, 1994). It is being gradually more used in nursing research, providing the means of generating theories grounded in the reality of every clinical practice. Nurse researchers use the grounded theory methodology because of its capability to deliver insight into a person's experience and make a positive impact as can be seen from many published researches (McCann & Clark, 2003). Wuest (1995) suggests that grounded theory is mostly appropriate in nursing as the researchers take an interpretation of the results and actions after having explored the informant's experiences. In this study, grounded theory is employed as a consequence of its relevance to nursing practice and the real-life problems of patients and family caregivers. This theory focuses on the family caregiving process and is integrally involved with the problems that affect the quality of caring for patients on HMV. Knowledge consequential from grounded theory research can also help nurses enhance the quality of nursing care in addition to providing nurses greater control in uncertain situations by assisting them understand what they are facing through explanation and by suggesting available approaches for implementation to manage better more effectively with this uncertainty.

Summary

The treatment of home mechanical ventilation has experienced a dramatic increase in Thailand for patients who have respiratory failure and require ventilation support. Although there are several advantages to HMV for patients such as prolonged life and improved clinical outcomes, HMV requires complex care support from family caregiving. Previous research on the caregiving process and experience were found to be related to adaptation, collaboration, and communication, contributing factors, caregiver burden and ethical challenges. Nursing intervention studies that provide clinical practice guidelines for discharge planning or technology for monitoring patients at home were also established. These studies were conducted in Western countries where the cultural context, healthcare system and technological facilities are different from those in Thailand. Moreover, family caregivers of patients requiring ventilator support may face the most extreme type of challenges among other groups of caregivers. This literature review shows that no knowledge concerning this topic in the Thai population exists and is, therefore, seriously needed. It is important for healthcare providers to understand the perceptions of family caregivers concerning care for patients who depend on HMV in order to provide optimal care support meeting their needs. Lastly, grounded theory methodology has been explained in terms of history, evolution, philosophy and how it is more appropriate than another qualitative studies and nursing practices.

CHAPTER 3

METHODOLOGY

The aim of this study was to identify a successful process of family caregiving for patients dependent on home mechanical ventilation (HMV) and to generate a substantial theory of the caregiving process. The grounded theory methodology was applied. Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008, 2015) strategy was explicate. The section is followed by data collection and analysis. Then descriptions regarding the establishment of the study's research trustworthiness and the protection of human rights are also discussed.

Study Setting Characteristics

The study occurred in Songkhla province in southern Thailand as shown in Figure 3.1. As part of Songkhla's administrative organization, the Provincial Health Department is responsible for public health, family hygiene and medical services for people residing in the province. Three tertiary hospitals are located in this provincial area including Hat Yai, Songklanagarind, and Songkhla hospital. Nevertheless, Hat Yai hospital, a hospital under the Ministry of Public Health, was selected for the study area because of the recruiting link of participants to chronic respiratory failure patients with HMV. This hospital is providing home health care services for ventilated patients in Songkhla province. The hospital has also established networks linked to secondary hospitals in the 16 districts: Mueang Songkhla, Sathing Phra, Chana, Na Thawi, Thepa, Saba Yoi, Ranot, Krasae Sin, Rattaphum, Sadaow, Hat Yai, Na Mom, Khun Niang, Bang Klam, Singhanakhon, and Khlong Hoi Khong.

The study was conducted at patients' homes located in the service area covered by Hat Yai hospital. The geographical area of districts and distribution of participant's location in Songkhla province are shown in Figure 3.2. The patient's home was selected as the study setting, because it was a real-life location where family caregivers provided care to their loved ones with HMV. Also, this enabled the researcher to observe first-hand the actual situation for each family. It was important to understand participant's contexts, since this was a longitudinal study requiring home visits, area familiarity, knowledge of how transportation worked, and how participants and the patient accessibility to care service in case of emergency.

Figure 3.1. Songkhla Province in Thailand

Map Source: https://www.chiangraitimes.com/thai-athorities-detain-200-suspected-turkish-refugees-in-songkhla-province.html: March 31, 2018

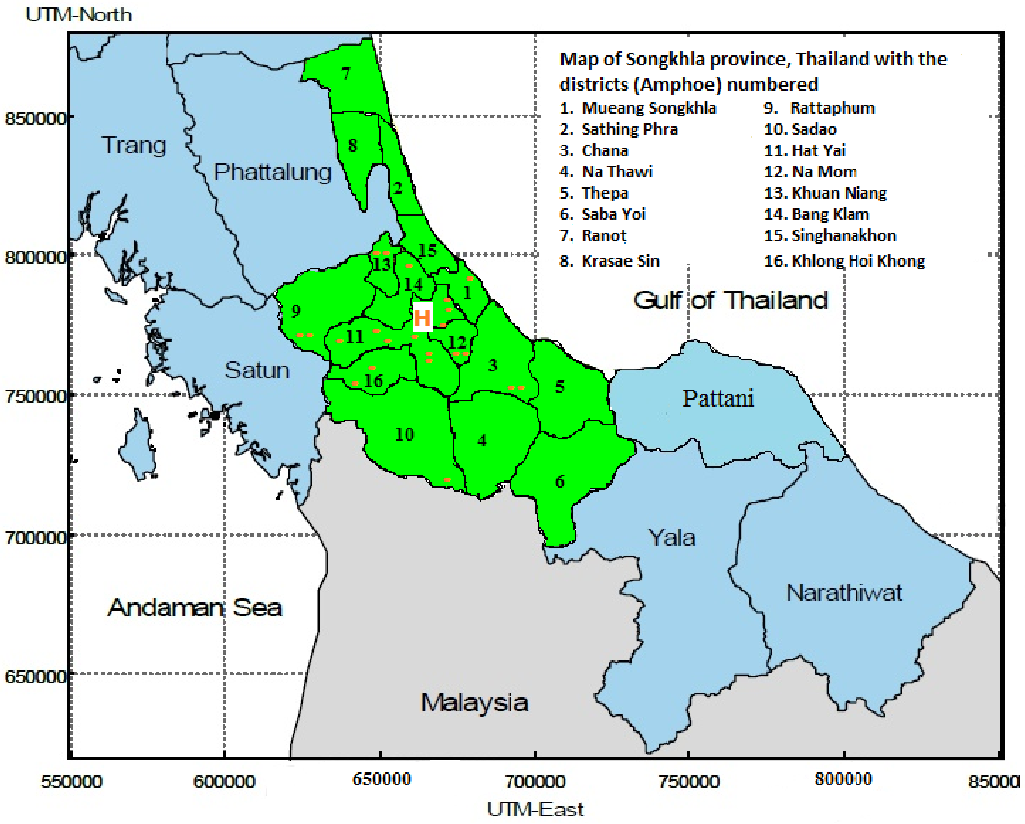

Figure 3.2. The Geographical Area of Districts and Participant's Location in Songkhla Province, Thailand

Applied with permission from: Demographic Trends Affecting Education Completion and Employment in Pattani and Songkla Provinces of Thailand (p. 21), by P. Thongchumnum, 2009, Prince of Songkla University, Pattani Campus. Thailand.

Study Participants

The study participants were primary and secondary caregivers who are family members and provided care for patients dependent on HMV living in Songkhla province. Moreover, participants were included if their patients met the criteria for successful care consisting of being able to wean off the ventilator and having a death without suffering. To define participants, the researcher used a specific method called *"theoretical sampling."* Theoretical sampling is the ability to provide information about varying situations to facilitate the researcher in developing a theory (Corbin & Strauss, 2008, p. 143). The selection does not focus on the individual or a certain number of participants; instead, it depends on data *saturation*.

Rationale for Selecting the Straussian Grounded Theory

Grounded theory as a qualitative methodology that aim is to generate a substantial theory. Substantial theory explains patterns of behavior that are relevant and problematic for the people involved (Glaser, 1978). As the purpose is to describe and explain the process of caregiving for HMV patient. The process involves interacting with the multidimensional aspects of caregiving and coping adjustments that made by family caregivers. As an inductive research, the necessity is to recognize data from the ground of the healthcare system, which influences the caregiving experience. The Straussian approach emphasizes the importance of identifying structural influences, in addition to contextual influences, and symbolic and interaction influences (Strauss & Corbin, 1990, 1998). The approach highlights the need to take account of both macro and micro influences on the phenomenon. This is reasonable and in accordance with the Straussian version.

Additionally, the approach of the Straussian version is particularly helpful and more flexible for the novice researcher to easily follow the process in adapting the procedures to different phenomena and research situations. Furthermore, the Straussian version is predominantly of a preliminary review, which enhances theoretical sensitivity. The researcher has some background knowledge and experience of caring for patient with HMV and also data from previous literature published before starting field work. For all of the above-mentioned reasons, the Straussian version was deemed appropriate to guide this study. The summary of the study’s methodological framework can be viewed in Figure 3.3

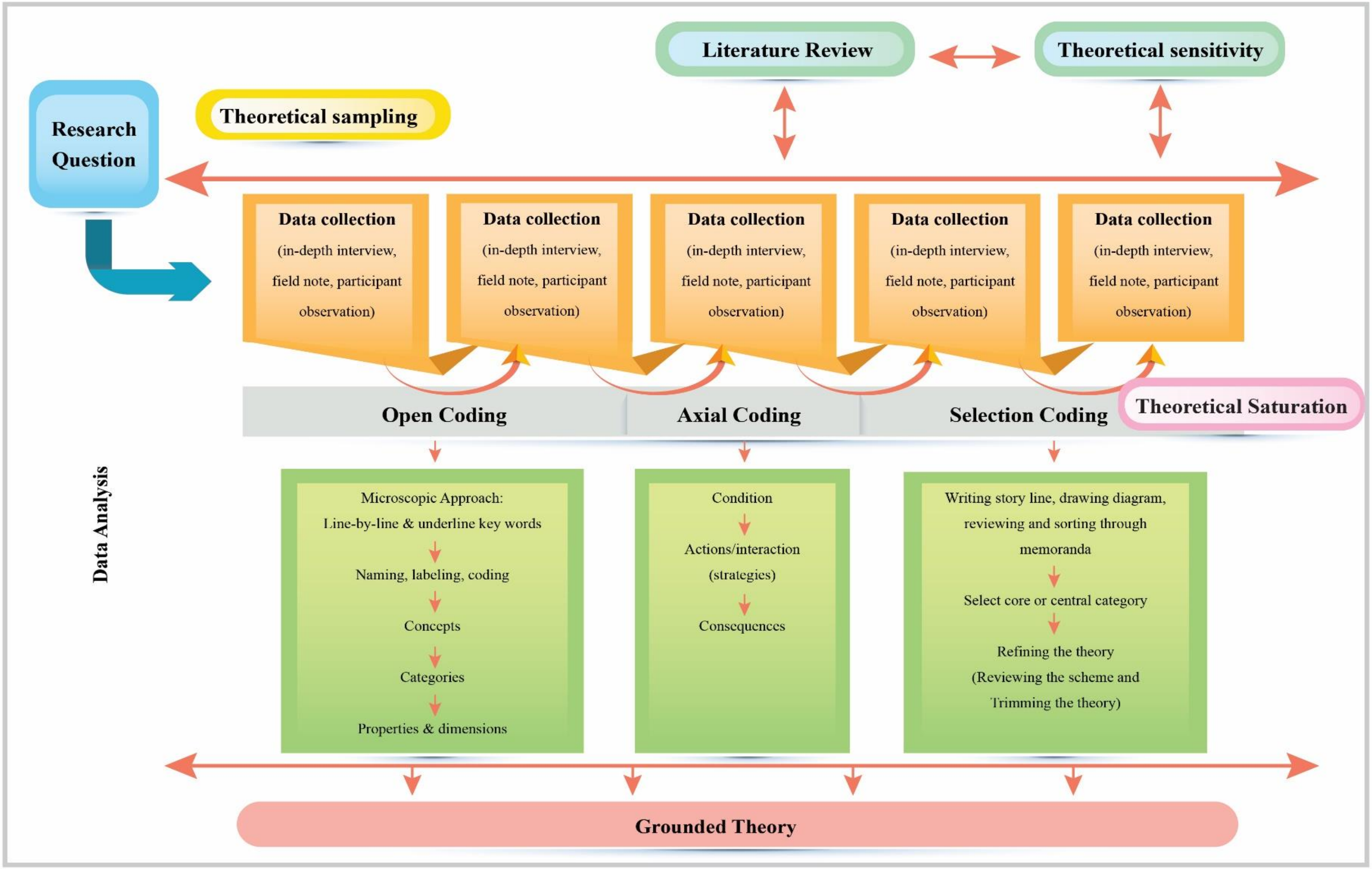

Figure 3.3 Methodological Framework

Data Collection

The data collection was classified into the following three phases: preparation, data collection methods, and sampling and data collection procedures.

Preparation

Before collecting data, the researcher had to prepare for conducting the study. An interview guide and recording forms were also developed in order to achieve a richness of data that would lay the groundwork for the theory.

Researcher. The researcher is of paramount importance when it comes to data collection in qualitative research. The researcher needs to be prepared to conduct methodological research, possess theoretical sensitivity, have a relevant understanding of the background, be aware of sub-cultures and be able to build trust between the researcher and participant (Råheim et al., 2016).

Research methodology: To improve knowledge of the research methodology, the researcher enrolled two qualitative research courses; 1) 641-815 Advanced Qualitative Research in Nursing and 2) 641-931 Advanced Qualitative Data Analysis at the Faculty of Nursing, Prince of Songkla University. The researcher learned how to collect and analyze data then practiced from the courses. The researcher also learned about qualitative research gaining both theoretical and practical insights from previous studies. Moreover, a preliminary study was conducted and the researcher piloted a study with two family caregivers who provided care for patients on HMV in order to practice analyzing issues of interest prior to the data collection process.

Theoretical sensitivity: The researcher gained knowledge about the ability to understand the meaning of data by reviewing family caregiving literature, and patients with HMV (see Chapter 2). As a result, the researcher has formulated ideas about the current state of knowledge in this study, the gap of knowledge regarding the real phenomena in order to generate new concepts from the raw data.

Researcher background: The researcher has five years of clinical ICU experience, particularly concerning patients on mechanical ventilation, and four years of clinical experience teaching student nurses. Using the validation technique of bracketing in qualitative research (Tufford & Newman, 2012), the researcher did not contaminate or skew the data. It was important that the participants' spoken words and feelings were understood and recorded in an unbiased manner. The researcher visited the families of HMV patients (as a member of the Hat Yai Hospital team in Songkhla Province) and observed care activities several times during a two-year span. After the visits, observation notes were recorded by the researcher and self-reflections were written in the field notes in order to learn more about the family caregiving process and family contexts.

Awareness of sub-cultures: The researcher is not native to Songkhla province nor the southern region of the country. However, by living in Songkhla province for three years, the researcher has gained extensive experience in observing family caregivers who provide care for loved ones with HMV. The researcher visited patients requiring HMV and their families to observe the care process enabling the researcher to gain invaluable insight into the values, behaviors, and attitudes of this sub-culture. Additionally, *differences in language and tradition* were also respected during home visits and preliminary interviews. The use of silence and reflective questioning gave each participant time to think and reflect over the researcher's questions. The interviews were audio recorded and conducted in Thai. However, for participants who spoke the local language, a nurse who was researcher assistant and lived in Songkhla province transcribed verbatim. The use of open-ended questions allowed the participant to open up and share many stories about caregiving experiences for their loved ones.

Trust between participants and researcher: To obtain more accurate data, the trust of the participants in the researcher is paramount. In this study, the researcher obtained data through the process of a prolonged engagement carried out through interviews and observations, an exhaustive cultural understanding, active listening to the language and perspectives of the participants that fostered and reinforced trust in the researcher. As a result, the researcher was able to gain the participants' confidence with the aim of providing accurate and unbiased data. This significantly improved research findings through intimate familiarity and the discovery of hidden facts and gems. The researcher learned to understand and adapt accordingly to various situations by visiting patients, participants and other family members at their homes.

Interview guide. An interview guide was used during the in-depth interviews, which was very helpful to the researcher in obtaining comprehensive data. However, in actual situations, the researcher could not strictly follow the order of the prepared questions. Flexibility was essential as it served to assist the researcher in data collection and objectivity (Appendix A).

Recording forms. The following recording forms were employed by the researcher based on memo writing (Strauss & Corbin, 1998): field notes, transcription notes, code notes, axial notes, theoretical notes and validation notes (Appendix B). These forms facilitated recording. Additionally, the equipment used to collect the data comprised an audio recorder, camera and computer that were prepared to ensure constant efficiency.

Data Collection Methods

The data collection methods were used in this study included following three domains: in-depth interviews, participant observation and field notes.

In-depth Interviews. An interview is a conversational method by which the researcher ability to gain access and then understand private interpretations of an individual's social realities. According to Denzin and Lincoln (2005), interviewing is one of the most common and powerful methods a researcher can understand human beings. Interviewing has various forms and uses. The most familiarity types of interviewing are group face-to-face, individual face-to-face, self-administered or mailed questionnaires, and telephone surveys. Interviewing can categorize to structured, semi-structured, or unstructured (Denzin & Lincoln, 2005). Regarding to Minichiello, Aroni, Timewell and Alexander (1995), an in-depth interview is a dialogue with a specific purpose, e.g., the dialogue between the participant and researcher the focuses on the participant's perception of self, life, and experience as stated in his/her own words. The decision to use in-depth interviewing as a data collection method is linked to the purpose of the study. If social reality exists as a meaningful interaction between individuals, then it can be grasped though the understanding of the other person's perspective, meanings, and interpretations. When meaningful human interaction dependents on language, the words their use, and the interpretations they create are of vital interest to the researcher. In-depth interviewing is also an appropriate technique for gaining access to the individual's spoken words and interpretations.

Moreover, Patton (2002) indicated that a qualitative interview should be open-ended question, sensitive, neutral, and clear to the participant. In-depth qualitative interviews are usually exploratory in nature and flexible. The interview style is conversational, unstructured, and the questions asked are commonly open-ended and considered to obtain detailed, concrete stories about the participant's experiences (Whyte, 1982). The aim of such an interview is not to identify objective truths or to conclusively test hypotheses but to assistance the researcher understands the participant's experiences and the conclusions the participants themselves have illustrated.

Participant observation - Although the means of data collection in this study was in-depth interviewing, participant observation was also involved in this process. Blumer (1969) claimed that interviewing is not enough to understand a participant's world; observation methods can also be beneficial to researchers. They allow the researcher to check and gain more for non-verbal expressions to define who interacts with whom and to understand how participants communicate with one another (Schmuck, 1997). Moreover, participant observation allows a researcher to confirm the meanings of the terms informants use in interviews, observe events that participants may be unable or unwilling to share and observe situations that informants have already defined in interviews. Thus, it makes a researcher aware of inaccuracies or distortions in the explanations provided by the participants (Marshall & Rossman, 1995). Also, the researcher must understand the participants and the contexts of living at home.

Field notes. Field note-taking is crucial to the process of data collection as this technique allows sociological and human elements to be captured soon after observation (Briks & Mills, 2011). Patton (2002) expressed that field note-taking records and tracks analytical insight which occurs during data collection. However, Corbin and Strauss (2008) differed in that field notes are data that may also contain conceptualization and analytic remarks. Therefore, in this study, field notes were composed of events and conversations that happened during the fieldwork, and contained contextual information about time, place and actors. This provided greater understanding of the situation. Moreover, reflective notes represent the researcher's personal experiences, reflections, and progressions while being in the field. However, when the researcher was doing fieldwork, interviewing, or observing, the researcher wrote down only key words. Field notes were written immediately after the fieldwork in order to remember the essence and accuracy of the situation.

Sampling and Data Collection Procedures

Participant sampling and the data collection process followed the following procedures delineated by Strauss and Corbin (1998): 1) open sampling, 2) relational and variation sampling, and 3) discriminatory sampling.

At the beginning of accessing and recruiting participants in ***open sampling***, a purposive convenience sample of family caregivers were selected. The selection criteria were unrestricted to ensure that theoretical sampling could follow. The selection criteria included a family caregiver who provided care for a loved one with HMV, Thai ethnicity, ability to speak and understand Thai, and residence in specific areas of

Songkhla. These participants were recruited by the suggestions of clinical nurses, Hat Yai hospital.

After receiving human right protection approval, the researcher met with the participants and spoke to them about the study. The researcher introduced herself to the participants and briefly described the study procedures in addition to answering the participant's questions. The researcher introduced herself to each participant as a PhD candidate from the Faculty of Nursing, Prince of Songkla University, without assistance from the hospital staff in order to eliminate pressure to join the study. After the participants had signed the consent forms and listened to the information (Appendix C), the participants selected the dates and times for the interviews.

All of the interviews were conducted at the participants' homes during the day. The interviews were conducted in Thai and audio-recorded. Although the main method for data collection in this study was unstructured in-depth interviewing, additional data was collected on age, marital status, level of education, socio-economic level, address, relationship to the patient, how long they have cared for the HMV patient at home by using a demographic data questionnaire (Appendix C). These simple questions about the participants' information could make them feel comfortable and relaxed. Then questions about caregiving were generated.

The researcher started the interviews with a general opening statement such as, "Please tell me about your experience in caregiving for a patient on mechanical ventilation at home." Probing questions were listed in the interview guide (Appendix A) encourage participants to provide more details on informative experiences (e.g., "In your opinion, what is caring for patient with HMV?", "Give me some examples of things that make you say it is suffering?"). In the first interview with participant, the interview guide was followed closely from item to item. While the structure and script of the interview guide was in process, the researcher noted that the participant could not elaborate and answered the questions in short. As a result, the researcher expressed feeling and discussed the participants' responses with the dissertation supervisor.

Thus, the modification of the interview was performed. The researcher used short note-taking to list importance issues, topics, key words, and questions requiring further probing or clarification during the interviews. However, any observed interactions, nonverbal behaviors, environmental situations, location and time of interview, the researcher's perceptions, and other relevant issues occurring during the interviews were recorded in the field notes immediately after the researcher left the participant's home. In addition, photograph of the home setting, care unit, and caring activity were taken after obtaining permission.

The next step was ***relational and variation sampling***. While the researcher collected data from caregivers via open sampling, the information was drawn from the analysis. It was influenced by *theoretical sampling* in order to find as many differences as possible in the data by way of the *contrary case* (Corbin & Strauss, 2015). The researcher extracted information from the participants' criteria in order to generate more comprehensive concepts based on the following criteria (Appendix E).

First, the issue of *accepting the caregiving role* should be addressed. Earlier studies have indicated that the rational information and variation sampling deals with accepting the caregiving role. Participants from previous studies have expressed that they had never planned to take the role of a patient caregiver on HMV. Consequently, they rejected that possibility. Therefore, through theoretical sampling, the researcher tried to find family caregivers who clearly perceived that they were the caregivers of their HMV loved ones in order to fulfill conceptions about the process and conditions. For that reason, individuals who agreed to provide care from the beginning assumed the caregiver role.

The second issue to be addressed was the *relationship between the patient and caregiver.* The literature review indicated that the relationship between the patient and the family caregiver was one of relational and variation sampling; all of the participants in the study were children of the patients. Therefore, in using theoretical sampling, the researcher was curious to discover whether the family caregiver could be another family member (spouse, parent or sibling) other than the patient's child.

Third, regarding the criterion of the caregiver's *gender,* participants who were included in this study were all females, even though selection should ensure the presence of both genders. Therefore, theoretical sampling was utilized to see if male caregivers are able to care for patients with mechanical ventilation at home.

Another important criterion of relational and variation sampling is the *lifespan of the caregiver.* The literature view pointed out that the caregiver's lifespan is one of the aspects of relational and variation sampling requiring the researcher's attention. Caregivers who were included were limited to adult caregivers. Therefore, the researcher needed to find elderly or younger caregivers who provided care for patients on HMV.

Discriminatory sampling was the final procedure. The sampling procedure during the discriminatory process had to be direct and deliberate, with conscious selection about who and what to sample to obtain the data required for theory generation. The procedure is described as follows:

At this stage, *the researcher selected the participants and documentation that maximized opportunities* for proving the story line, correlations between categories, and for filling in poorly-developed categories. During this process, the researcher returned to the old site, documents and participants or went to new ones to generate essential data that can be collected. Furthermore, concerning *theoretical saturation,* the common rule in a study of grounded theory is to theoretically sample until reached saturation in each category (Glaser & Strauss, 1967). The data saturation means until: 1) the category is well-developed in terms of its properties and dimensions demonstrating variation; 2) no new or relevant data emerges regarding a category and 3) the relationships among categories are validated and well-established (Strauss & Corbin, 1990, 1998). In this study, participants were recruited until the researcher is confident of having obtained satisfactorily rich descriptions, categorical development and has the desired variation. The correlations between categories are validated and well-established. The data collection stopped at 22 participants and researcher realizes that there is no new data derived from the analysis of each code.

Data Analysis

The Strauss and Corbin (1998) and Corbin and Strauss (2008, 2015) analysis methods were used in order to guide data analysis. Strauss and Corbin version of grounded theory study indicated that data collection and analysis were conducted together and initiated with the first interview. In addition, memos and diagram methods were also helpful to draw visual images that portrayed conceptual relationships. They could be expanded to new ideas that would improve theoretical sensitivity, but also gave direction to the research process. Theoretical sensitivity provided the researcher with insight, gave meaning to the data, greater capacity to understand, and the capability to separate pertinent facts and notions from the ones that were not (Strauss & Corbin, 1990).

Data Analysis Method

Data analysis was carried out by using three methods: open coding, axial coding, and selective coding (Corbin & Strauss, 2008, 2015; Strauss & Corbin, 1990, 1998).

Open coding - Open coding is the initial phase of the grounded theory analysis. The researcher first analyzed the data collected from each case separately, because of the need to understand individual cases. Then cross-case comparisons were performed. During this phase, concepts were classified and established in terms of their dimensions and properties. The same incidents and events were grouped together and coded in order to capture similarities.

Axial coding - Axial coding involves sorting information and searching for patterns. Typically, the processes of open and axial coding are not separate or sequential but proceed together. The in-depth interview data were coded and grouped into categories during open coding, and their linkages were then compared and examined during axial coding stage. Categories and their properties and dimensions were generated simultaneously as relationships were constructed. Sub-categories were linked to categories in several relationships and followed the paradigms of causal conditions, action/ inter-action strategies and consequences.

Selective coding - The condensation of categories, the determination of a core category and its relationship with other sub-categories, and the further modification of categories were performed in the last phase. These represent selective coding. Similar data was clustered and conceptually labeled. Then the concepts were categorized. Next, categories that were organized and linked by relationships, conditions and dimensions were developed. Lastly, a model was constructed. Every category in both open and axial coding was compared and linked with the core categories. These correlations were then validated through comparison with existing and new data until reach the data saturation.

Memos and diagrams

Corbin and Strauss (2008, 2015) identified that writing memos and doing diagrams are included in analysis as well as qualitative research work. Several types of memos are involved, namely, theoretical notes, code notes, and operational notes (Strauss & Corbin, 1998) (Appendix B). Memos and diagrams were produced by the researcher that was quite descriptive and helpful for expansion purposes. The researcher wrote memos and drew diagrams during each analysis process in order to ensure participant accuracy. The emphasis was on producing uncontaminated and unbiased data.

Theoretical Sensitivity

Theoretical sensitivity is defined as the researcher's personal qualities. Glaser (1978) suggested that theoretical sensitivity is gained by a preliminary review of the literature. Similarly, Schreiber (2001) claimed that in reviewing literature, a researcher becomes aware of personal risks and limitations which can hinder category development. Additionally, the analytical process as well as professional and personal experiences are also sources that can further influence theoretical sensitivity (Strauss & Corbin, 1990).

In this study's process of data analysis, theoretical sensitivity was implemented in order to generate data during the process of comparing themes from literature. The literature reviews guided data collection and assisted in concept and indicator development. Furthermore, the researcher was better able to explain what is going on based on the participant data. Later, the relationship process between deduction and induction came into play with the intention of building the core categories.

Data Analysis Procedure

After interviewing, the audio recordings were transcribed by the researcher and assistant researcher. The transcriptions were read line-by-line repeatedly in order to develop data content sensitivity at the analytical level. This follows the principle, think at an abstract level, and see into the data. A constant comparison approach was also used to analyze the information content of each interview. Next, the interview transcripts were recorded in Thai and the open coding method was used. Code cards were developed in order to illustrate the information of each code concerning respective definitions, interview examples, and other code relationships when actions happened or did not happen. During the analytical process, theoretical ideas, hypotheses, and other related issues were noted in memos. The initial data coding and analysis were used to direct the focus of later interview questions by modifications or additions. These initial findings were also integrated into the comparative sample groups according to theoretical sampling techniques.

The subsequent interviews were conducted simultaneously with the coding, comparison and analysis of the data obtained. Along with the open coding process, the investigator examined the memos in order to identify relationships and properties among the codes. The main categories were gradually identified and continuously refined in later interviews. After three interviews (preliminary study), the participants' understanding about the caregiving for their loved one with HMV was linked to their management behaviors and their feelings were addressed. Then the participants willing adopted the caregiving role once they fully accepted and adjusted to their chronically-ill patients on HMV. Consequently, the study focused on exploring the process the participants had assumed and adjusted to their caregiver roles, their path of sustaining behavior, and their methods for managing and thriving in their caregiving role with other family roles and life demands. Each emerging category was explored until there was no new or additional information from subsequent interviews.

Concurrent with this process of axial coding and selective coding, the process of establishing relationships between categories and model integration were carried out. The researcher drew conceptual linkages between the discovered categories and between the categories and codes using data logic. Explanatory models were sketched and constantly modified as new data was obtained. Memos representing the researcher's hypothetical ideas were recorded throughout the analysis process. Memo sorting was also performed in order to identify further additions into the working theory and to suggest other correlations among the categories.

Being in the midst of a storm and labyrinth of suffering, doing one's best to move on, and achieving blissfulness of mind in the caregiving role with other responsibilities were chosen as the core categories. These categories were logically linked with other categories and sub-categories, to form an explanatory thriving in a family caregiving model. Data collection provided a dense description of properties and categories in addition to confirming the hypothesized relationships suggested by previous data. The conditions under which each participant's behavior occurred or did not occur were identified. Non-relevant properties and categories were removed to delimit the theoretical model. Data collection was halted when there was no new or additional information from later interviews. Additional data from relevant literature reviews was also used to better understand and validate the emerging theory. Peer debriefing and negative case analysis were conducted periodically throughout the data collection and analysis phases. Peer debriefing sessions were conducted on an average of two times a month with both advisors using face-to-face meetings.

Translating and Writing the Theory

The translation process in this study carried out with the researcher's full awareness of the complexity that might pose a threat to the validity and reliability of the data. In the circumstances when there are no equivalent words between Thai and English languages, the researcher provided a detailed definition of the words based on the participant's perspective. In addition, although the interviews are conducted in Thai, some participants used a southern dialect, which differs from the researcher's native Thai dialect. However, the researcher has lived in Songkhla province for three years and is quite familiar with the local dialect. In the cases where the researcher did not understand the participant's words, they were asked to clarify the meaning of these words.

Moreover, the research assistant who was a native speaker of the local dialect provided a transcription verbatim. The researcher was the only person who translated the material throughout the study in order to maximize the consistency and reliability of the translated data. Initially, emerging codes, categories, properties and quotations were written in Thai. Thereafter, the abovementioned were translated into English by the researcher and a linguistics translator and then back-translated in order to ensure that the meaning of the words and grammar were accurate. To ensure the accuracy of the translated data, a Thai qualitative nurse researcher was asked to validate the accuracy of the translated material. The validation was conducted by means of back-translating the English version of the data into the Thai language and comparing the back translation with the original data. The Thai qualitative nurse researcher earned her master's and doctoral degrees from the United States and the United Kingdom, respectively, and is currently working on a number of international projects.

Establishing Research Trustworthiness

Trustworthiness is defined as the honesty of the data collection from or about the participants' inclusion. It is also a term that reflects the overall quality of the process in qualitative study (Lincoln & Guba, 1985). Errors in qualitative research occur in two ways during the processes of both data collection and analysis. In order to consider the features, it can create error reflecting the overall quality of the process in research. Therefore, trustworthiness is important in evaluating the study's worthiness, particularly in terms of the researcher designing ways to increase the rigor of the study, and for the reader to assess the value of the findings (Krefting, 1990).

Moreover, the researcher should employ a great deal of care and quality of craftsmanship at each step of the research process (Kvale, 1994). Lincoln and Guba (1985) recommended that trustworthiness involves the establishment of credibility, transferability, dependability and confirmability. In this study, the researcher followed strategies that satisfy these four criteria: credibility, transferability, dependability, and confirmability as described below.

Credibility

Credibility is defined as the confidence that the researcher has in the truth of the study's findings. The credibility of qualitative data is supported by the researcher acting several procedures (Lincoln & Guba, 1985). Glaser and Strauss (1967) highlighted that the researcher should provide an extensive abstract presentation of the overall framework and its principal associated theoretical statements. Using a categorized procedure for analyzing data, it permits readers to appreciate how the data analyst achieved his theory from the data. It also enhances credibility. There are five techniques to enhance credibility: prolonged engagement, namely, persistent observation, triangulation, external checking or peer checking, and member checking.

Prolonged engagement refers to an extended time period of data collection. Its goal is to have an exhaustive understanding of the culture, language and the views of the participants through interviewing and observation. In addition, prolonged engagement is important for an intense participation in that it improves research findings through intimate familiarity and discovery of hidden facts

(Kielhofner, 1982) . It is also vital performance because, as rapport increases, informants may volunteer a different quality or type of information. To accomplish the study credibility, long-term contact of three to five visits for each case over six months of the study were done to identify the prominent characteristics of the interviews and observations. In addition, it was vital that the researcher understood and got exhaustive data from each participant.

Persistent Observation refers to a technique that ensures an understanding and a deepness of experience in adding to the broad scope encouraged through prolonged engagement (Lincoln & Guba, 1985). In this study, the formal and informal home visits to all 22 participants accounted for more than 50 visits. In addition, the researcher not only focused on the participants, but also on other family members, neighbors and friends who were present in the home. This confirms the study credibility, which represents the degree of confidence about the truth and context of the setting.

Triangulation is defined as the use of more than one approach to the investigation of a research question in order to enhance confidence in the study findings and also minimize distortion from a single data source or researcher bias (Krefting, 1990) . There are four types of triangulation (Lincoln and Guba, 1985): data triangulation, investigator triangulation, theoretical triangulation, and methodological triangulation.

1) Data triangulation involves data collection through several sampling approaches such as variety of participants, different times, and social situations. This study involved sampling strategies, objectives and theoretical sampling. Different visit times were also used to support completeness and convergence of data.

2) Investigator triangulation is defined as the use of more than one researcher in the field to gather and interpret data. The researcher was closely supervised by two field advisors in Thailand. Data analysis and discussion were performed twice a month.

3) Theoretical triangulation is defined as the use of more than one theoretical position in interpreting data. This, new data emerging from the fieldwork was compared with prior data and other literature reviews in order to find similarities and differences. Symbolic interactionism and pragmatism were instilled along with a philosophical orientation. In addition, this new fieldwork data was compared with prior data and other literature reviews in order to find similarities and differences.

4) Methodological triangulation is defined as the use of more than one method for data collection such as participant observations, interviews, and field notes. In this study, multiple sources (interviews, observations, field notes, and memos writing) of data gathering were used to promote completeness and convergence.

External checking or peer checking refers to the use of an expert panel or an experienced colleague to check the categories developed from the collected data. During this process, the availability of the informants' verbatim accounts was helpful for examiners in critically assessing the interpretations made from direct quotes. The findings in this study were submitted to peer checking by two Thai qualitative research advisors and another two co-advisors from the USA who had experience with qualitative research to support the credibility of the data.

Member checking refers to the continuous testing of informants regarding data interpretation to ensure that the researcher has correctly translated the participants' perspectives into the data. The process of member checking was undertaken after the researcher had analyzed the emerging categories and participants who gave feedback via the member checking form (Appendix B).

Transferability

Transferability or applicability refers to the generalization of study results. This means the extent to which the data findings be able applied to other settings (Lincoln & Guba, 1985). Krefting (1990) also suggested that a key factor is the transferability of the data to the representativeness of the participants for that specific group. Regarding transferability in this study, the researcher provided dense participant background information on family, home setting, and any other patient data to clearly show the transferability of the data.

Dependability

The dependability of qualitative data refers to whether a particular result can be reported with accuracy, consistency and stability (Krefting, 1990). Glaser and Strauss (1967) suggested that a study must be general to be applicable to varied situations within the essential area and not only to a particular type of situation. It need also permit the user part of control over the structure and process of daily changing situations over time. At this stage, the researcher had ongoing discussions with the two advisors. Copies of the participants' narrative transcripts and coding were shared with them to confirm the accuracy and consistency of process analysis for Thai language and meaning. In addition, analysis was validated and confirmed for the coding categories and the framing concept. Moreover, translation of the categories, sub-categories, and concepts were completed and verified by the researcher. Data confirmation was performed by a native English speaking consultant who has lived in Thailand for 10 years and two co-advisors in the USA.

Confirmability

Confirmability states that data interpretation can be described and confirmed by following an accurate process unaffected by researcher bias (Guba, 1981). This strategy involved an external auditor trying to follow the natural history or progression of events in a project in order to understand how and why decisions were made (Krefting, 1990). Moreover, Lincon and Guba (1985) suggested the following six domains of records that can be contained within: 1) raw data (video and audio recording and field notes), 2) data reduction and analysis products (condensed notes, quantitative summaries, working hypotheses), 3) data reconstruction and synthesis products (thematic categories, interpretation, and inference), 4) process notes (research design strategies, procedures, and trustworthiness notes), 5) materials related to intentions and dispositions (research proposals and field journals), and 6) instruments information (pilot study forms, survey formats, and schedules).

In this study, thick descriptions were obtained through detailed and systematic field notes. Thoughts and reflections were written in a separate journal for each case. Each journal started with the first day of the HMV visit with nurses, nurse case manager and the participant. It included a record of all contacts until the last day with the participant (Appendix B). Repeated interviews plus systematic field notes of repeated observations provided a thick description for confirmation of the findings.

Protection of Human Rights

Ethical issues and risks for participation comprised of human subjects' detailed observations, confidentiality and anonymity, and inducements. The researcher used many steps toward protecting the rights of the participants who participated in the study. Prior to undertaking the research, the proposal, interview guide and participants consent form were reviewed and approved by the Institutional Review Board (IRB). The Faculty of Nursing, Prince of Songkla University (Appendix F) sought permission to conduct the study. The consent form was written in both English and Thai (Appendix C: English and Thai consent forms). The research purpose, methods and participant rights were explained and communicated in Thai.

To commence the study, permission was obtained from the *authorized person* of each study site to conduct the research before recruiting the participants. Then the researcher explained the study both verbally and in writing to the participants to show respect and awareness of others at home. Participants were informed that there would not be any risks involved, and that they had the right to remove themselves from the study at any time without repercussions. If they agreed to participate in the study, then written consent was obtained at this time.

Confidentiality and anonymity were guaranteed, and it was emphasized to the participants that they and their family members would remain anonymous. A code number and pseudonym were assigned to each participant instead of using real names. The interview audio recordings were conducted only at locations where privacy was assured. The researcher was the only person who could listen to the audio recordings, and no copies were made. In addition, the researcher transcribed all of the audio-recorded interviews by using a password protected personal computer. The audio contained interview files that were secured on a hard disk and separate from other data. All of the data will be deleted after the data is no longer useful for the purpose of the study. The participants' names and addresses leading to their identity will be concealed when the research findings are published.

As for inducements, the participants were clearly informed that they would incur no costs or payments. The only benefit mentioned was that they would have contributed to the field of caring for individuals with HMV. It was also pointed out that the only real inconvenience to the participants was the sacrifice of their time. The participants were asked to be interviewed twice at a private place of their preference.

During the interviews, permission was also requested for audio recording and note-taking of the interviews. They were instructed to give genuine descriptions without any pressure and feel free to discuss only topics they were comfortable with. In addition, the subjects were told that they could request to stop the recording when the topic was something private. Participants were also made aware that they could ask questions, refuse to answer questions or stop the interview at any time.

The anticipated risks to participants included psychological discomfort or distress related to disclosure of an array of feelings or the caregiving situation itself. During the interviews, five of the participants became emotionally upset when talking about the deterioration of their patient or their obligation to their patient. They expressed feelings of pity or distress about watching their patient's health deteriorate. Psychological discomfort was minimized during the interview by the researcher's attention to the participants' reactions. However, all of the participants expressed satisfaction and a willingness to be interviewed. After the interviews, the researcher provided further knowledge and answered any questions about caregiving procedures or activities. It is believed that the participants gained an indirect benefit from the study by inheriting an appreciation of their own caregiving situation.

Summary

This qualitative study utilized the grounded theory methodology to explore experiences and management behaviors for family caregivers caring for patients on HMV. The participants were interviewed at their homes by using interviewing techniques that employed open-ended questions. The audio-recorded interviews were conducted in Thai. The constant comparison method was utilized, while data collection and analysis were concurrently performed until no new data surfaced. The initial data was also coded and analyzed in Thai. The data codes, categories, properties and important quotations were translated into English by the researcher. The translated material was validated for accuracy by using the back-translation technique.

CHAPTER 4

FINDINGS AND DISCUSSION

This chapter presents empirical findings to answer the following research question: *"What is the successful family caregiving process for patient dependent home mechanical ventilation (HMV)?"* and *"How do family caregivers move forward and harmonize caregiving role into their daily life?"* The description was organized into two sections. First, the characteristics of participants and patients were described. Then, the theoretical findings, focused on a family caregiving model of HMV patient, is entitled *"Thriving in Family Caregiving"*. This model encompasses three major processes: *being in the midst of a storm and a labyrinth of suffering, doing one's best to move on, and achieving blissfulness of mind.* Participant statements from interviews were also provided. In the discussion, the study focused on summarizing the study findings and relate them to the existing literature and research in order to highlight the contributions this study makes. Moreover, similarities and differences of family caregiving experiences of HMV patients from other studies were discussed.

Findings

Characteristics of the Participants

Participants in the study were 22 family caregivers from 16 families. Summary explanation of the participant and family's context are shown in Appendix G: Description of participants. Participants' demographics are also shown in Table 4.1.

Twenty-two family caregivers who defined themselves as a primary caregiver (n=16) and secondary caregiver (n=6), with 15 being female and 7 being male. The age of participant ranged from 23 to 78 years old with an average of 50. Ten participants were early in adulthood (20 to 45 years old), nine were in middle adulthood (46 to 65 years old), and three were elderly caregivers (>65 years old). The majority of the participants were married (14), while six were widowed or divorced and two were single. The participants had primary school education (eight participants)–Thailand's mandatory educational requirement. Seven achieved secondary school (high school), six earned a bachelor's degree, and one had a vocational diploma. In addition, all the participants were Buddhist.

Regarding the participants' physical health, the majority did not have an underlying health concerns (17 participants). Two participants had hypertension, and one had diabetes mellitus. The remaining two had past illness with spinal surgery and a brain injury respectively. In regard to, the relationship of the caregivers to their ventilated patient, the numbers are the following: adult child (13 participants), spouse (3 participants), mother (2 participants), sibling (2 participants), uncle (1 participant), and son-in-law (1 participant).

Caring for patients with HMV ranged from 1-62 months with the average being 12 months. Eight participants had a range from three to six months. Five participants ranged from 7-12 months and five others from 1-2 months. Two participants provided care from 2-3 years and two other have been provided care more than 5 years. In addition, this study included participants who had experience in caring for patients of less than three months due to meeting the successful caregiving definition of being able to wean off the ventilator successfully or death without suffering at home. Participants' employment background showed that seven participants were farmers/ rubber planters. Six were unemployed and, one was retired. Four participants were business owners (i.e. construction, fireworks, laundry, and silver plating). Two were street vendors (i.e. food and craft), and the remaining two were official government workers.

Regarding household monthly income, it ranged from 1,000 to 40,000 Baht (32 Bath = 1 $). Four ranged from 10,000 and 15,000 and four others from 30,000 to 40,000 Baht. Three were in the range between 5,000 and 10,000 and three others less than 5,000 Baht. Finally, one ranged from 15,000 to 20,000 and one others from 20,000 to 30,000 Baht. Ten combined incomes from their own work and from other family members. Five earned income from other family members only and one was a self-earner. Unemployed participant derived their income from other family members. The majority lived in rural areas (12 families), and the remaining four lived in areas classified as suburban.

Table 4.1

Demographic Characteristics of the Participants (N=22)

Characteristic	**N**
Family caregiver role	
Primary caregiver	16
Secondary caregiver	6
Gender	
Female	15
Male	7
Age (years old) (Range = 23-78; Means = 50.23; S.D.= 14.24)	
Early adult caregiver (20-45)	10
Middle adult caregiver (46-65)	9
Elderly caregiver (>65)	3

Table 4.1

Continued

Characteristic	N
Marital status	
Married	14
Widowed/ divorced	6
Single	2
Education	
Primary School	8
Secondary School	7
Vocational / Diploma	1
Bachelor degree	6
Physical health status	
No underlying disease	17
Hypertension	2
Post spinal surgery	1
Post brain injury	1
Diabetes mellitus	1
Religion	
Buddhist	22
Relationship to ventilated patient	
Adult child	13
Spouse	3
Sibling	2
Mother	2
Uncle	1
Son-in law	1

Table 4.1

Continued

Characteristic	N
Duration of caring ventilator dependent patient at home until the present/ died/ weaned off ventilator (Range=1-62 months; Means=12.6)	
1 – 2 months	5
3 – 6 months	8
7 – 12 months	5
2 – 3 years	2
5^+ years	2
Employment status	
Farmer/ Rubber planters	7
Unemployed	6
Business owner (construction, fireworks, laundry, silver plating)	4
Street vendor (food and craft)	2
Government worker	2
Retired	1
Household Monthly Income (Baht) (Range = 1,000-40,000) (n=16)	
< 5,000	3
5,000 – 10,000	3
10,001 – 15,000	4
15,001 – 20,000	1
20,001 – 30,000	1
30,001 – 40,000	4
Sources of household income (n=16)	
Self	1
Other family members	5
Self and other family members	10
Residential area (n=16)	
Rural	12
Suburban	4

Characteristics of Patient Related to Family Caregiving

Patient characteristics related to family caregiving include four aspects: 1) personal characteristic, 2) health-care coverage 3) cause of prolonged ventilator, and 4) level of physical functioning and consciousness. These characteristics are outlined in Table 4.2.

Sixteen patients (nine females/seven males) with HMV were included to the study. Patients' age ranged from 29 to 97 years old with the average being 69. The largest group of patients (9) were elderly (> 65). Four patients were identified as middle adulthood and three were identified as early adulthood. As for marital status, seven patients were widowed or divorced, six were married, and three were single. Twelve had a primary school education, two had secondary school status, and two other obtained diplomas. All were Buddhist.

Regarding health-care coverage and services, the Universal Coverage Scheme (UCS) covered the care of 10 patients. Four had the Civil Servant Medical Benefit Scheme (CSMBS), one had The Social Security Scheme (SSS), and one paid cash. Ten patients had acute respiratory failure with chronic conditions: Alzheimer disease, stroke, chronic fracture femur, breast cancer, and heart failure. Two patients were in a coma post cardiac arrest. In addition, four patients had neuro-muscular disease: Guillain-Barre-Syndrome, Myasthenia gravis, genetic of spinal muscular atrophy, and accidental spinal cord compression.

The levels of physical dependence and patient consciousness were related to the level of caregiving. All patients were totally dependent on 24-hour care via a five-point assessment scale, 0 being completely independent to 5 being totally dependent (24-hour nursing care). The level of patient consciousness was assessed by AVPU (Alert Verbal

Pain Unresponsive) where six patients were alert and orientated, four were unresponsive, three were responsive to voice, and three other were responsive to pain awareness.

Table 4.2

Demographic Characteristics of the Patient (N=16)

Characteristic	N
Gender	
Female	9
Male	7
Age (range) (Range = 29-97; Mean=69; SD=22)	
Early adult (20-45)	3
Middle adult (46-65)	4
Elderly (>65)	9
Marital status	
Single	3
Married	6
Widow/divorced	7
Education	
Primary School	12
Secondary School	2
Vocational/ Diploma	2
Religion	
Buddhism	16
Health-care coverage	
The Universal Coverage Scheme (UCS)	10
The Civil Servant Medical Benefit Scheme (CSMBS)	4
The Social Security Scheme (SSS)	1
Cash (out-of-pocket)	1

Table 4.2

Continued

Characteristic	N
Cause of prolong ventilator	
Acute respiratory failure with chronic condition (Alzheimer, stroke, chronic fracture femur, breast cancer, and heart failure)	10
Neuromuscular disease (Guillain-Barre syndrome, Myasthenia gravis, genetic of spinal muscular atrophy, and cord compression)	4
Coma (post cardiac arrest)	2
Level of physical dependent	
Totally dependent-24-hour nursing care	16
Level of consciousness	
Alert and orientated	6
Responsive to voice	3
Responds to pain	3
Unresponsive	4

Summary - Beginning Interpretations

The study findings were presented in a reciprocal and reflective nature. While the coding paradigm serves to guide the analysis and results, it also demonstrates how each category of the family caregiving process is interconnected and influential based on condition, action, and consequent. Moreover, the findings illustrate a family caregiving process for patients with HMV and keep within the grounded theory tradition of data analysis. Moreover, participants's name were replaced by pseudonyms, name of Thai flower. Table 4.3 provides an overview of the thematic analysis of the participants' stories of their experiences in caring for a patient with HMV.

Table 4.3

Core Category, Categories, Sub-Categories, Sub Sub-categories, and Paradigm Model of Family Caregiving Process of a Patient with HMV

Core Category	Categories	Sub-categories	Sub Sub-categories	Paradigm model
Thriving in Family Caregiving	**Being in the midst of a storm and a labyrinth of suffering**	**- Feelings of incompetence**	- performing care procedures - managing the ventilator	Condition
		- Managing competing demands	- high level of care required - multiple role responsibilities	Action
		- Being overwhelmed	- visible costs of care - invisible costs of care	Consequence
		- The quest for meaning in care	- why me? - what is the meaning in care?	Consequence
	Doing one’s best to move on	**- Being inescapable**	- patient lingers - assignment - daughter - lineage	Condition
		- Making up one’s mind	- self-encouragement - seeing good things - letting go	Action
		- Making-meaning in care	- sense of duty - Tob-Tan Bun-Khun - Bun-Bab	Action

Table 4.3

Continued

Core Category	Categories	Sub-categories	Sub Sub-categories	Paradigm model
		- Learning to care	- observing - practicing and receiving feedback - seeking essential information and guidance - trial and error	Action
		- Adjusting family life	- fitting of family life and care activity	Action
		- Seeking support	- healthcare institution - nurses - other family members - sub-district organization	Action
		- Being in charge of care	- managing daily living - handling ventilator at home	Consequence
	Achieving blissfulness of mind	**- A sense of pride**	- appreciated by people in community - improvement of patient's health - promoting peaceful death	Condition
		- Realizing meaning in care	- legacy of love	Condition
		- Providing humanized care	- a sense of belonging - maintaining conversation - promoting social interaction - striving for merit-making	Action
		- Living life in balance	- familiar caring with HMV - live a normal life	Consequence

Overview of Thriving in Family Caregiving Model

Thriving in Family Caregiving Model in this study, the core category that was generated from participant descriptions. The model reflects the transformation of caregivers' views and adjustments about providing care for their ventilated patient at home. This transformation encapsulated from sense of failure and suffering to succeed and harmonize in providing care. Following this process helped the family caregivers and patients dependent on HMV live more comfortably, and ultimately achieve blissfulness and harmony in their life. The model is explained with three categories including being in the midst of a storm and a labyrinth of suffering, doing one's best to move on, and achieving blissfulness of mind. Each of these categories has several sub-categories.

Being in the midst of a storm and a labyrinth of suffering was the beginning stage of the thriving in family caregiving model for their loved one dependent on HMV. The family caregivers in this study revealed that caregiving for patients with HMV exacerbated their suffering and stress. With the patient needing a ventilator and care to extend life, the family caregiver became a vital person in this process. *Feelings of incompetence*, as a condition, instantly appeared when the doctor prescribed HMV for the patient. The caregivers perceived that their loved one was acutely ill. These types of patients needed advanced technology and professional care. The participants felt that they lacked professional knowledge and necessary skills required to provide adequate care for them.

In addition, participants in this study felt they suffered from *managing competing demands*. Not only did they have a 24-hour caregiving role, but also had roles of mother, wife, and income earner. These caregivers tried to manage these competing demands of their multiple roles. However, the participants felt handcuffed and reflected their experiences as a major disruption in their own life. *Being overwhelmed*, both visible and invisible costs of care, and the quest for meaning in care consequently emerged. Study participants were not only overwhelmed with financial burden but the invisible costs of physical exhaustion, psycho-emotional, and spiritual strain. There was frustration, anger, and stress knowing that the patient was totally dependent on technology. There was also a constant fear that if something went wrong death was imminent. Meanwhile, many questions emerged repeatedly all the time and went unanswered. Some examples were why me? and What is happening in my life? It was *the quest for meaning in care.* In this stage, the family caregiver indicated their feelings were like a boat being in the midst of a storm - strong wind, torrential rains and pounding waves all around. They had never known when does it end? Family caregivers who could not go through this suffering stage remained in the midst of a storm and a labyrinth of suffering. They still continued to ask the question, why me? and felt sorry for themselves.

However, for some one who could move forward they went to the next stage, **doing one's best to move on**. *Being inescapable* from the caregiving role initial emerged as a turning point and a condition of the stage. The participants had been forced by other family members to be a primary caregiver because they were at the most appropriate position. Moreover, they had to confront the realization that when patient was clinically stable and ready to be discharged to home, it had to be someone who provide the necessary care to their loved one. The participants stated that they had no choice because they could not let patient die without caring. In addition, in this stage, being overwhelmed and the quest for meaning in care from previous stage still had remaining questions unanswered. These conditions were pushing participants to take actions and re-construct their thoughts about giving care for their loved one with HMV to overcome situation of being in the midst of a storm and a labyrinth of suffering as well as being inescapble.

In this point, family caregivers poured their love, concern and energy into caring for the patient as doing the best they could. They fought hard for the patient's independence. Upon returning home, many adjustments were made in order to move on from the labyrinth of suffering. *Making up their mind* was the following step that participants had to manage and adjust their perception about caring for their loved one with ventilator at home. The use of positive thinking, Buddhist beliefs, socio-cultural influences, self-encouragement, and letting go of current thinking were all ways the participants psychologically coped with their predicament. Moreover, *making meaning in care* was a reason to provide care that the participant stated in order to move on and overcome the difficult situation by determining what's most meaningful to the participant and their patient. Participants also had to re-frame their role in terms of *learning to care*, *adjusting family life*, and *seeking support* to handle daily living and high-tech patient care.

Consequently, the participants felt confident to manage care for their loved one with HMV as *being in charge of care*. The participants felt that they could sustain their role of caregiver to patient and family. They acquired the ability to maintain daily living and high-tech care for their loved one at home. In this stage, they also sensed that the patient could achieve a higher quality of recovery or reach a peaceful death that dependent on their illness condition. These positive outcomes represented successful caregiving as perceived by the participants.

Some participants who got stuck in this stage and felt they had already provided the best care for the love one as they could. Returning to the stage of being in the midst of a storm and labyrinth of suffering were also occasionally happening when they meet an obtacle event in care. These also affected the quality of care and well-being of both patient and family caregivers in the long run. Conversely, some participants who could get through the process of care they move to the next process.

Eventually, ***achieving blissfulness of mind*** was the result of having success in the family caregiving process. Participants who had enrolled in this stage they had feelings of not only success in improving the patient's health but also happiness, self-fulfillment, and intrinsic satisfaction that resulted from their caregiving role. The participants in this study have a feeling of success resulted in a peace of mind as *a sense of pride.* In addition, *realizing meaning in care* is the spiritually ultimate meaning and life values were reached. A deeper more meaningful caregiving role lead to a legacy of love. These were conditions and also a turning point that enhance participant's understanding and wish to do the best care for their love one with HMV.

In this stage, *providing humanized care* as action that the participant respond to their legacy of love in achieving blissfulness of mind stage. It was a holistic understanding of humanized caregiving: physical, psycho-emotional, and spiritual concern. Consequently, *living life in balance* was also a result of the blissfullness of mind. The participants found the middle path between the role of caregiving and family. They obtained their own sense of balance. They could do for themselves to find a middle way that worked just right for them. Getting through achieving blissfulness of mind process helped raised their acceptance of patient death and happiness level leading to transformation, and then, in turn, a sense of bliss. The Model of Thriving in Family Caregiving is exhibited in Figure 4.1.

As Figure 4.1 reflects a dynamic process of the thriving in family caregiving model. The three big circles are three main stages of the model, being in the midst of a strom and a labyrinth of suffering, doing one's best to move on, and achieving blissfulness of mind. The green color in each circle represents the condition of each stage while the red color is actions to respond to particular conditions. The yellow color is the consequence of each stage. In addition, the arrow reflects that the caregiving journey of these participants was dynamic. The participants moved back and forth these three stages depending on the conditions and Thai socio-cultural factors including hierarchy relationship, traditional gender role, changing family structure, Buddhist belief of law of Karma, and Buddhist value of gratefulness. Details of participants' caregiving jourvey in each stage are narrated as followed.

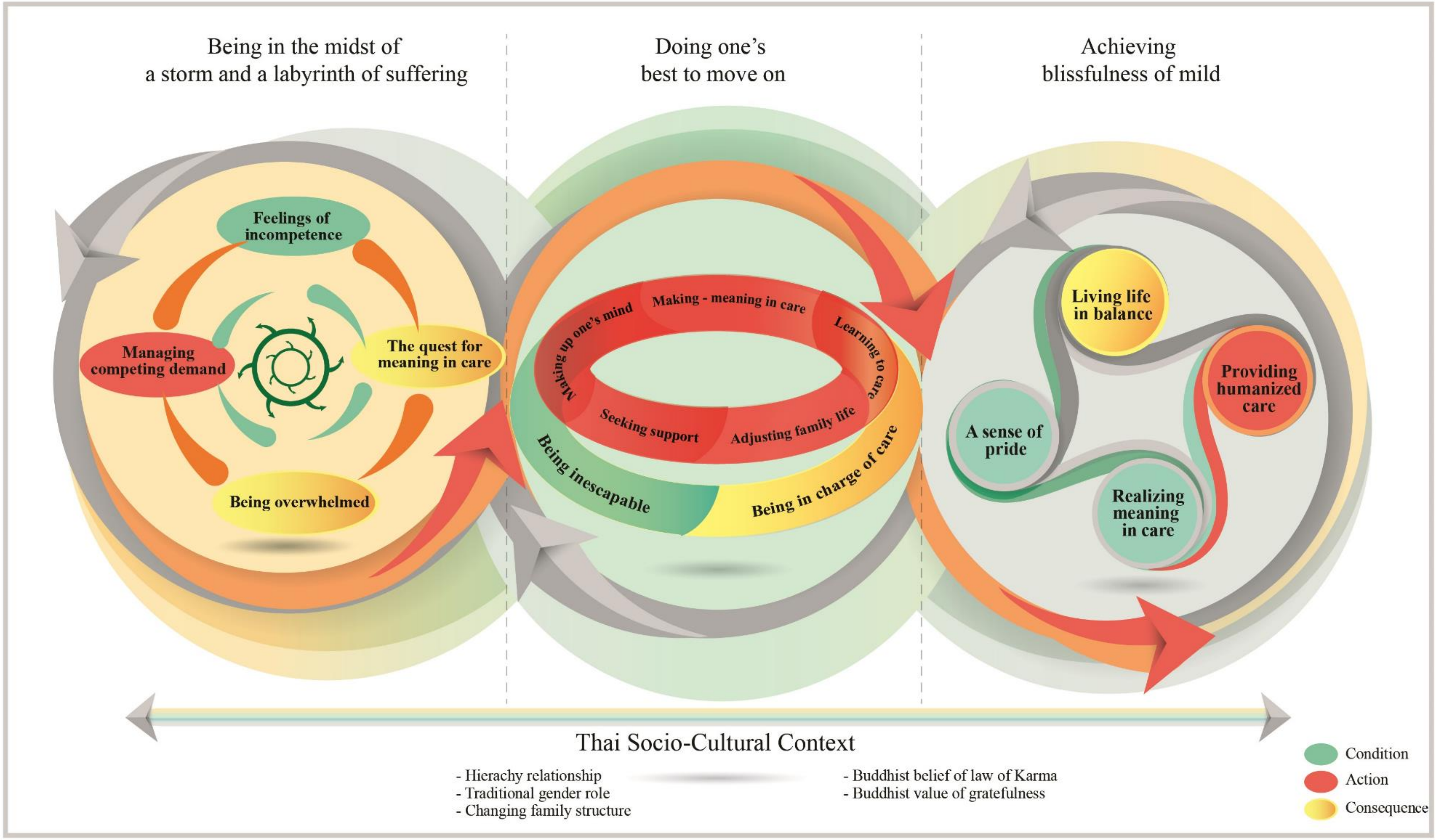

Figure 4.1 Model of Thriving in Family Caregiving

Categories 1: Being in the Midst of a Storm and a Labyrinth of Suffering

Participants in this study recalled their experiences of first knowing about a discharge plan and becoming a caregiver of patients with HMV as they were in the midst of a storm and in a labyrinth of suffering. It is defined as living with stressful events and no way to escape. The participants perceived giving care for their loved ones with HMV as their labyrinth of mysterious walkways. There is no guide to aid them, to assist them in a proper path or process to take; thus, what the participants perceived their situation as falling in a labyrinth of suffering. Four sub-categories emerged from the participants' description about being in the midst of a storm and a labyrinth of suffering: *feeling of incompetence, managing competing demands, being overwhelmed, and the quest for the meaning in care.* The model is exhibited in Figure 4.2.

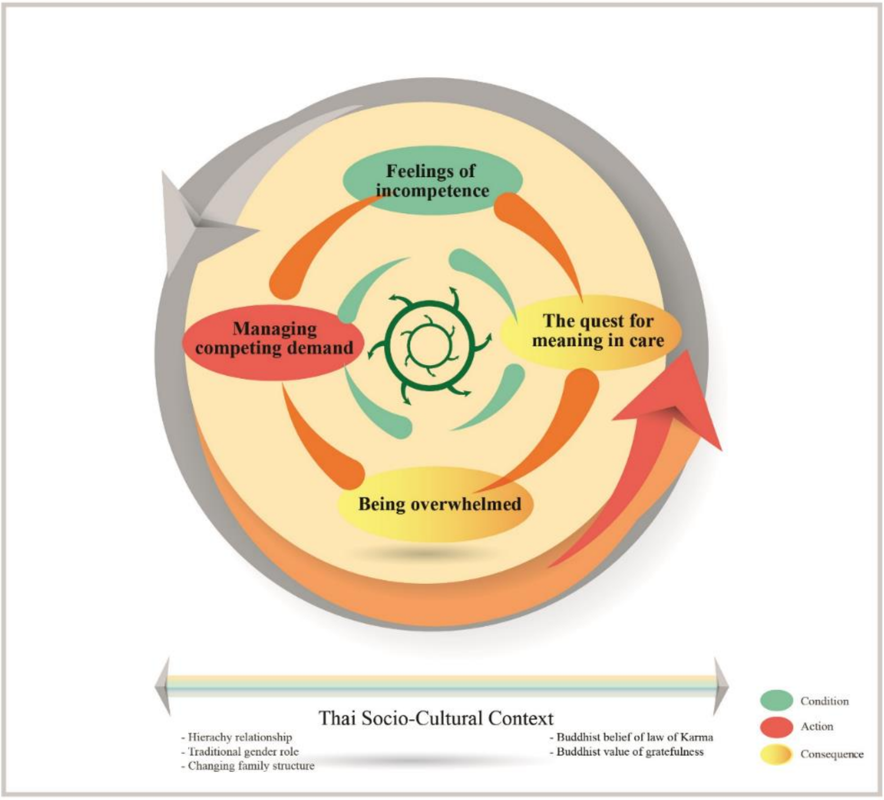

Figure 4.2. Model of Being in the Midst of a Storm and a Labyrinth of Suffing

Feeling of Incompetence

The feeling of incompetence is the initial response of being in the midst of a storm and a labyrinth of suffering that the participants had when faced with a caregiver's role of a patient with HMV. Participants who cared for their love ones with HMV viewed the ventilator as representing advanced technology used for sustaining life. Caregivers perceived patients who received these kinds of life sustaining technologies should be in the care of health professionals. As a result, the caregivers felt they lacked the competency to manage complex technologies for patient life-threatening conditions. In addition, they perceived that patients with ventilation support had a higher demand of care. Several care procedures such as suctioning, ventilating with self-inflating bags, and tube-feeding required professional skills which they did not possess. These care procedures also needed to be performed carefully and cautiously as they might affect the patient's well-being. Furthermore, these patients had tracheostomies which led to communication difficulties. The caregiver participants felt if they were unable to understand patient care needs, proper care would be compromised.

Consequently, when doctors discharged ventilated patients from hospital to home, participants felt that they were incapable of performing this procedure and lost control of the caregiving situation. The participants perceived if they could not manage future caregiving outcomes, something terrible might happen. It was the participants' feelings of perceived danger or surrounded threat that they were being pushed into the midst of a storm. To the participants, a line between life and death of the patient was closely. They were also worried that inadequate care would be harmful to the patient and consequently lead to the patient's death.

As Saiyhud, a 78 years-old female, stated she was the caregiver for her son (34 years old) diagnosed with myasthenia gravis and needed HMV breathing support. She spoke of feeling afraid and believed that her inability to care for son who had complex needs and required complicated care procedures. Saiyhud revealed that she felt anxious and was scared to perform procedures such as suctioning and cleaning tracheostomy. Additionally, with worsening of her son's symptoms and ventilator problems, she could not handle these situations. She also felt she was very ill-prepared and would like the patient to remain in the hospital. She stated:

> Never done it…I feel offended… I am afraid that I will insert a suction catheter too deep…something like that…I feel a thrill of fear…fear… fear! fear! I didn't learn in this thing…I fear that I can't do it…When the doctor wants to discharge the patient, I felt uncomfortable…because I cannot help him. But the doctor said he would provide ventilator and suction machine. I am afraid that if the patient gets worse, I don't know how to help him… by staying in the hospital, we feel warm…not matter if he survives or not…it warms our heart. (Saiyhud)

In addition, Chongko, a 43-year old daughter who had been taking care of her father (accidental cord compression) needing ventilation support describes her situation to support for the inability to care. She was afraid and lacked confidence when providing care for her ventilated father at home. Chongko mentioned suctioning that could cause of patient breathlessness, pain, or unexpected death, these mad her feel stress. She described:

> I have never done this before. I don't know how to do it. Nurses tend to think it's not a big job. But for me it is a big deal. I lack experience in taking care of any person I never had any experiences of washing a patient…I'm afraid and stressed, I can't take care of him. Suction is a big problem for me that it hurt my emotion. I don't know where's the catheter is placed? Is he hurting? I am afraid that I am wrong and his condition worsens…. As a patient condition, I know that I must turn

> position him every 2 hours but I think it’s too much of a task for a caregiver and I am not confident. I’m afraid that I will kill him. (Chongko)

Another, Mali, 42- year old female participant, who was providing home ventilated care to her mother for five years. Prior to caring for her mother, she had never studied or had any experience in caring for ill patients. The situation she feared the most was mismanagement of the tracheostomy tube resulting in her mother’s inability to breath and unexpected death. Mali said:

> At first when I came back home, I feared that I couldn’t take care of her (patient). When my mother (patient) stayed in the hospital, the doctors, nurses, and my older sister could help. At home, it was only me. I was fearful I couldn’t do it…at that time, I were alone… I feared with worsening symptoms I couldn’t handle them. Because I had never studied in this field, I didn’t know if I could do it. I was afraid… I was afraid that I couldn’t provide care properly, if she had stayed in the hospital, the healthcare staff knows how to deal with care. But for me, I just guess what to do. I am afraid that if the tube (tracheotomy tube) came out, I couldn’t put it back…that worries me. (Mali)

Study participants further revealed a lack of competence not only in performing care procedures but also in managing the ventilator. All participants recalled their experiences during the first few months after taking the patients back home. They felt worried and fearful of a power outage or a machine malfunction, they would not know how to handle the situation. In particular, how to manage the patient or a threatening situation. They realized that the ventilator was important for patient’s breathing and operated by electricity. Without electricity, the ventilator doesn’t work, show alarming sound, and English language appears on the mornitor. It could mean that the patient cannot breathe and could die. Two other participants shared their experiences of worry, fear, and not knowing how to resolve problems they felt as being in the midst of a storm and a labyrinth of suffering.

> When the respiratory machine alarm sounded, I got so excited. I was afraid that he (patient) would stop breathing, and I couldn't get him to the hospital in time. (Kalong)

> An electrical shutdown occurred about 2 am. It made me very worried. The ventilator was show alarming sound. . . Fu. . Fa. . Fu. . Fa. . (the ventilator sounded) . I called the Metropolitan Electricity Authority, but nobody responded to my phone call…I said '*Tai Laew'!* (exclamation shock) what should I do? I was stressed about this situation - how should I do?... At that time, the electricity shut down and I were calling, and the machine was alarming… Ouch !What's this? …everything was happening at the same time…Sometimes on the ventilator monitor produced 2 or 3 lines of English that I didn't understand. I don't know which button to press. It should be the job of hospital staff not me. (Chaba)

Managing Competing Demands

Managing competing demands reflected feelings of tension in the caregiving role and caregiver's elevated concern about the patient's well-being. Caring for patients with HMV required attention to detail. Most patients were completely dependent on high levels of care. Each day the participants spent nearly 24 hours providing bedside care. A high level of responsibility regarding the care, the safety and other advanced caring needs were recognized by the caregivers. The participant may have mistaken clinical deterioration for an equipment problem. This care is often of a highly technical nature and is required for large parts of the day and often night. Caring for their HMV patient, two participants, Payom and Ratree, described what they did each day at home.

> Each day, I was devoted to taking care of my father (patient) for almost 24 hours. I lived in this room with him and worried most

> about the respiratory machine working and infection. I had to clean the room early every morning. (Payom)
>
> I can't neglect her (patient), I always stay with her…At 2 pm. I turn her and give her some water then 3 pm. then at 4 pm. I have to change a diaper and feeding duties. At 9 pm., change a diaper again. When I saw everything was done, then I went to bed. (Ratree)

In addition, a participant in this study expressed that before becoming a caregiver, there were many tasks, responsibilities and obligations one needed to complete. Some participants worked full-time jobs, took care of other family members, and raised their children. When taking patients back home, participants reported they felt overwhelmed. However, participants often were more focused on the patient care than on other responsibilities like their own emotional and health needs. As two participants, Chaba and Fuengfah who cared for their loved one with respiratory failure and needed ventilator support explained feelings of managing competing demands. They expressed:

> I must manage my roles both caregiver and family. As a caregiver of a ventilated patient (father) who must be in sight all the time; while, roles of wife and mother who takes care of family/children could not neglet. I think the family role is also important and can't be damaged. I have to act as a housewife, because it's my duty before caring for my father. Sometimes, I felt tired particularly on busy mornings. My children will go to school, I have to prepare their uniforms, food, and take them to school. Meanwhile, I have to complete a bed bath for my ventilated father who can't move. I do this everyday… Do it alone! complete bed bath, turn body position from left to right, change bed sheet…(Sigh)…Tired! After I have done everything for my father (patient), I had also to provide care for my mother who is frail elderly. (Chaba)
>
> Now, I've a feeling that my life is non-stop and turbulent…many things I have to do, I am busy all the time…I feel as if I'm running all the time…When I wake up in the morning, I take care

> of my baby then provide care for my husband (patient), and then go to work at the minimart. It feels like a circle and non-stop running. (Fuengfah)

One male participant, Champee, shared his experiences of facing managing competing demands. He cares for his mother who was initially diagnosed with breast cancer, which led to lung metastasis and respiratory failure needing total ventilator support. Yet, he still had to work. As a result, Champee had to manage both tasks simultaneously.

> I can't be only a caregiver. I have to work, because I have to earn money for livelihood and family. One person has to do two things at the same time. For work I can leave, but in providing care I can't leave. I have to do this as the first priority. (Champee)

Being Overwhelmed

Being overwhelmed by caregiving is the consequences of feeling incompetent leading to managing competing demands. It is a psycho-social context that is a result of interactions between an individual and other people they know. Participants in this study implied that being overwhelmed by caregiving is a temporary block - unable to think clearly due to their emotional feelings making them experience too many distractions. Under these conditions, participants viewed that being overwhelmed was a *cost of care.* Cost of care is defined as caregivers had to pay or spend both *visibly and invisibly*. Visible cost is the economic impact of family caregiving, caring for the ventilator at home patient. The caregiver must pay more for medical devices and other caring supplies. It is not only the ventilator that is expensive but also other machines and instruments including suctioning mobile and oxygen concentration. In addition, essential medical supplies such as suctioning cateter, sterile water and electrical costs had to be paid. Participants in this study felt stress knowing that they had to buy those machines and many supplies.

As Chongko, participant of a father who suffered from complete cervical cord compression and needed a ventilator for prolong life revealed her feeling of stress when the doctor suggested to buy the ventilator machine. She was not sure how long her father would live. Paying large amounts of money to buy equipment can be a cost and an investment. The participant also indicated that she did not have enough money to buy devices, and she was hoping for donations from the hospital. As a result, Chongko negotiated to keep her father on ventilation support in the hospital. She stated:

> When the doctor told me to buy a ventilator machine, I felt dizzy. The machine's price is quite high. I think if my father dies then what would I be able to do with the machine. Who will use it? keep it, useless… Um… I think it's cruel! He (doctor) told me to buy the ventilator machine. It is two to three hundred thousand baht; meanwhile, my father (patient) may live only another 4-5 months. After he's dies. Who will use it after him? The doctor said that I can afford it but that is from his perspective not mine. (Chongko)

Some participants expressed being overwhelmed with the visible cost of care. Financial stain increases with increasing costs of ventilation use at home. One has the initial machine cost along with maintenance, material supplies and utilities: suctioning tubes, sterile water, wound dressing materials, cleaning the ventilator circuit, electric, and transportation. They stated:

> Each month I spent a lot of money to buy suction tubes and sterile water to put in the ventilator matchine. The hospital gave me only 10 pieces. So, I decided to buy new each time 500 baht per 100 pieces of suction tube and 10 bottles of sterile water at the drug store. (Champa)
>
> It has been a negative effect for me. Since my father came home, the electric bill has tripled or quadrupled. (Chaba)

> Although I didn't have enough money to buy the ventilator, I had to find it… I also had to pay for medicine that was not included in the healthcare coverage… I had spent a lot of money for medical supplies and materials such as gloves, sterile water, normal saline, suction tube, and food for patient. In particular, I bought about three or four hundred pieces of suction tubes, but they don't last long. These are my worries regarding the high cost of care. (Ratree)

Participants in this study also revealed that decreasing household income became a family problem as a visibly cost. As patient care with ventilator at home is a 24-hour process, participants could not earn income. Some indicated insufficient monies for the family and had to borrow money. Those participants felt overwhelmed and stressed. They expressed:

> After my dad (patient) stayed at home, all our savings were gone, because I couldn't work and take care of my father. At that time, I had to manage everything. When my father became stable and mom with him it allows me to work at night in the rubber plantation, to earn money. The economy was poor, low prices for rubber meant low household income. Meanwhile expenses were high. A lot of money was spent for caregiving materials, food, and electricity. I felt so tired from big money problems. (Payom)
>
> Previously, my mom and I worked to earn money. Now I had to care for my bother (patient) who is dependent on ventilator. I be here to care for him fulltime to allow my mom to go out to work in farm. Life now is more difference due to lack of money. Household income has declined. It wasn't like before. (Banchuen)

Moreover, *invisible costs* included the participants' physical, psycho-emotional, and spiritual health in their caregiving role. Being full-time caregivers of ventilated patients at home affected the participants' well-being. Some got sick after taking care of their loved one with HMV due to physical exhaustion. Participants indicated that they did not always get enough sleep, felt working all day and night. Sleep disturbances also occurred from causes of suctioning, ventilator alarms, noisy ventilators, and patient coughing. Several times they had to wake up hourly to check ventilator to ensure that their patient was still breathing and ventilator functioning. This caused them to feel tired and sleepy daily. Some participants expressed about their sleepless experiences:

> I was 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 must wake up for suction to clear airway two or three times a night. Sometimes, I must get up to massage her. Afterward she feels better, can then go to sleep. (Champee)
>
> I do not sleep well at night, I always hear my dad (patient) cough so I have to get up. (Pikul)

Psycho-emotional stress is another invisible cost of care that was expressed by participants in this study. It is defined as feelings of tension in caregiving situations and the caregiver's anticipatory concern and responsibilities about the patient's condition. Emotional stress was a psycho-social factor that is a result of interaction between a participant and their patient and other people according to their roles. Fatigue, weakness, low energy, and lack of motivation in daily life usually occur. As Chaba, 42-year- old participant who provided care for her HMV father of three years felt so *disheartened with giving care and others family roles* at times that she felt tied, fatigue, and did not want to wake up some mornings. She said:

> I feel tried 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). Don't want to make a bed bath for him. (Chaba)

Another is Chongko, 43-year-old female participant providing care for her HMV father, a victim of complete spinal cord compression from a motorcycle accident. She shared her difficulties and struggle into managing competing demands. She mentioned that care situations make her stressed and angry. She expressed:

> My life is cheotic, but I don't deny the caregiver's role. I am tired, but I am always focused on my father (patient)…I felt stressed with both my work and caregiving role. Sometimes I feel mad, but I tried to tell 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 to my mom (who is a secondary caregiver) why didn't you tell me before I came 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 always so busy. I complained to my mom, and she became angry at me saying I didn't't take care of my dad (patient) enough. Constant quarrelling with my mom is another source of stress to me. (Chongko)

Some participants in this study also felt *upset* when the patients showed their displeasure and would not talk to them. Thanklessness or the lack of appreciation of the caregiver caused feelings of being slighted. Two participants, Kajohn and Mali said:

> I try to help her (patient), but it's not the same as what her children do for her. Her children do very little, but she admires her children. I do more for her, but she doesn't appreciate it. I am only her son-in-law. (Kajohn)
>
> Sometimes I have regret. When others come, she (patient) gives them money. But never gives to me. She will give me only when I need to buy something for her. I need to beg her …Sometimes she makes a wry face if I don't do something for her immediately. She does not speak to me. When I ask, *"Do you want to eat something?* She still is silent. I don't know what angers her…Everybody has their own life but not me, I stay here

> with her all the time. When she calls or coughs, I will look after her. When she stands up, I will go to her immediately. (Mali)

Another feeling is *guilt*. It is defined as the participant's feeling of own fault in failing to give proper care or behaving in an improper manner towards their patient. The participants expressed how they sometimes forgot or were remiss in some caregiving activities. The guilt about incorrect behaviors towards their patient comes from these practices: position turning, not giving a certain kind of care, or incompleteness of care. Moreover, guilt is defined as a caregiver's expression of realization that they sometimes behave in an inappropriate way towards their patient. The participant expressed:

> I feel guity that the reason my father (patient) got sick is (bleeding in his stomach) because of my poor care… I blame myselves first before I blame the patient. My father is blind and on ventilator so he can't eat by himself, he eats as I take for him. (Chaba)

Social isolation and social withdrawal are other psycho-emotional stresses. They have feelings of restriction and disconnect or a lack of social activities with their friends, because caregiving responsibility consumes most of their time. Participants in this study put their patient as their top priority. They cut out other activities deemed not important compared to caregiving. However, staying at home with the patient all the time and a sense of separation from other friendships were revealed.

As Pradoo, 33-year-old male participant expressed his experience of giving care to his brother who was diagnosed with cardiac arrest and prolonged ventilator use at home. He perceived that inattentiveness to the patient on a ventilator, the machine not working or disconnected to the tracheostomy tube are reasons given where the patient could die. One has to be at the bedside continuously. Consequently, Pradoo stated that he feels like a bird in a cage, could not go anywhere. He expressed:

> If my brother (patient) wasn't ill, I could go anywhere. But now, I can't go and have to stay at home. I can't leave him alone, because I am concerned that his symptoms will worsen… I feel like a bird in a cage. The bird may be luckier than me, because it can fly out to find food and come back in the evening. But, I can't. I can't let him alone, because he needs caregiving all the time such as beware ventilator function, suction, and feeding. I have also to prepare food for him and give it via the nasogastric feeding tube… Sometimes, I feel tired and disheartened that I can't leave home, I would like to go somewhere for relaxing but I can't… That is why I feel like a bird in a cage… Previously I could go anywhere. (Pradoo)

Moreover, *spiritual suffering* is another invisible cost experienced by participants. It represents a loss of control, a burdensome to others, a sense of isolation, and an intense fear of patient's dying. Participants in this study indicated that an absence of sexual activity and time spent together as a married couple was spiritually stressful due to spousal dissatisfaction. Among young adult participants, couple problems were typically linked to the participant's 24-hour caregiving role. Two participants with young spouses, Chaba and Mali, spoke about the being overwhelmed as spiritual suffering of the caregiving role:

> When I took care of my father (patient) at the beginning, I had to watch my father and mother downstairs. Couldn't go anywhere…He (my husband) said our family is not like a family anymore. He told me that we should have time to talk and live together …But I always focused on my father. I could not go upstairs to sleep with my husband. (Chaba)

> Sometimes he (my husband) complains that we don't slept together… he was angry because he goes to work and comes home we didn't have sextual activity… we cannot sleep

> together...it’s once in a while… (long sound) … I don’t want to argue with him (husband) because I don’t want a divorce. He said that he is unhappy. He has said many times that he would like to go back to his home town… It's awkward, I think in my mind. The relationship between my mother (patient) and my husband is not good. My mother does not like him (husband). But, we can live together as we have an attachment…Both of us love each other. We should live together. (Mali)

Moreover, when providing care, one of spiritual distresses is time restrictions. Banchuen stated that she could not go out, hangout with their friends or join other activities in the village even though she would like to. She has declined several invitations from her friends and, consequently, they have stopped calling or inviting her to events. She said:

> Sometimes I was disheartened, because I couldn’t go away from home to a cerebrate a party with friends (Tears flowing). A party close to my home that I would like to join. However, if mom (secondary caregiver) had not stay at home. I couldn’t leave my brother (patient) alone. I am afraid that electricity will be turned off, and he can’t take care of himself (Tears flowing again). If mom couldn’t stay at my house, I couldn’t go the party even though I would like to…Now, nobody invited me to the party, because they knew that I couldn’t go. (Banchuen)

Fear of death was also a feeling that the participants revealed as spiritual suffering. It relates to a participant’s feeling of the passing of there loved one. Being separated from those who they are intertwined is frightening. The greatest fear of the participant is that the patient stops breathing and dies, and they cannot help or take them to the hospital. The participant’s perceived that allowing the patient to die caused great sadness and a feeling that they were killing their patient. Those participants were also very fearful of the ventilator alarm, because it meant the patient had irregular breathing. The participant felt unsure on how to manage and help. They stated:

> Excited, fearful, I do not know what to do? It (ventilator) was alarming noise like this… (ventilator sound) …fea!!… I do not know what to do… Afraid that my mother will have irregular breathing and go into shock (stop breathing) I don’t know what to do … I feel sad if my mother passed away. (Tears running down, said shivering sound and wipe her tears) We have lived together a long time, then she leaves me. (Champa)

> When the respiratory machine alarmed, I’m so excited. I afraid that he will stop breathing and can’t go to the hospital in time. (Kalong)

> It might be sadness, like I take care for her (patient) all the time. Then she dies at me. If it’s happen at hospital, no problem. Like I can’t get over this situation. But being at home, it’s memorized in my heart all the time. Because I live with her. I fear that dying of mom will stuck in my mind. (Mali)

The quest for meaning in care

Another element with being in the midst of a storm and a labyrinth of suffering participants encountered during this stage was the quest to find meaning in providing care. It is defined by the participants themselves asking questions to find answers with meaning. In this stage, participants were trying to connect the caregiving role to themselves. It is also a beginning period of the spiritual journey that caregivers undertook that encouraged spiritual growth during the most difficulty of times. Participants were so immersed in the drudgery of caregiving, they did not have time for reflection. When the participants felt overwhelmed and exhausted, many questions would arise and left unanswered. They would continue searching for answere to re-occurring questions. They felt as though they were caught in a whirlpool without escape. This became their labyrinth of suffering.

As Chaba, young adult female participant providing care for her HMV father expressed her experience of searching for meaning in care as endless. Such questions arose - why me? Why do I have to be the caregiver while the patient also has other children? When does the caregiving role end? What has happened to my life? What do I need to do to care for my loved one? How do I do it? She said:

> I, myself, tried to search for answer. Ah! while my father (patient) has many children, why nobody come? 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… many concerns (to do)… I don't have this kind of experiences. 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 does it? 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)

Later on, Chaba reflected that her journey is similar to rowing a boat in the ocean without ever seeing the shore. She elaborated further;

> (My life) is like a floating boat … floating continuously and endlessly…that's my father. We cannot set up (his life)…. The doctor told that he can live for three years. Sometime, it cannot tell or predict…I don't know how long he will be alive. Now, it's been two years, how long will he alive? .... I can't say when the end will come and where the end is. Whenever it will be, will be. If it reaches the land, whenever will be, will be. …(I am) not sure… I must continue to row until the end whenever that is. I know that day will come… but I don't know how long… for month or for year. (Chaba)

Categories 2. Doing one's Best to Move on

"*Doing one's best to move on*" is defined as the stage in which the participants reconstructed their thoughts about caring for their loved ones with HMV. They must adjust their thinking to accept and manage the caregiving role accordingly. Participants in this study moved on to this stage concurrently with the first stage. As being in the midst of a storm and in a labyrinth of suffering, the participants were aware that every minute of the patient's life was meaningful and the patient's life was in their hands. They had endured suffering and attempted to find strategies to overcome any difficulties they encountered. The participants mentioned that they could not waste their own time as being in a whirlpool of chaos and suffering. Therefore, they have accepted their role by adjusting their mind and managing any obstacles. This allowed them to sustain the caregiving role and improve the clinical outcome of the patient. Seven sub-categories as strategies emerged from the participant's description to encorrage themselves to move forward in caregiving role: *being inescapable, making up one's mind, making meaning in care, learning to care, adjusting family life, seeking support, and being in charge of care.* The sub-categories are listed with specific coding are shown in figure 4.3.

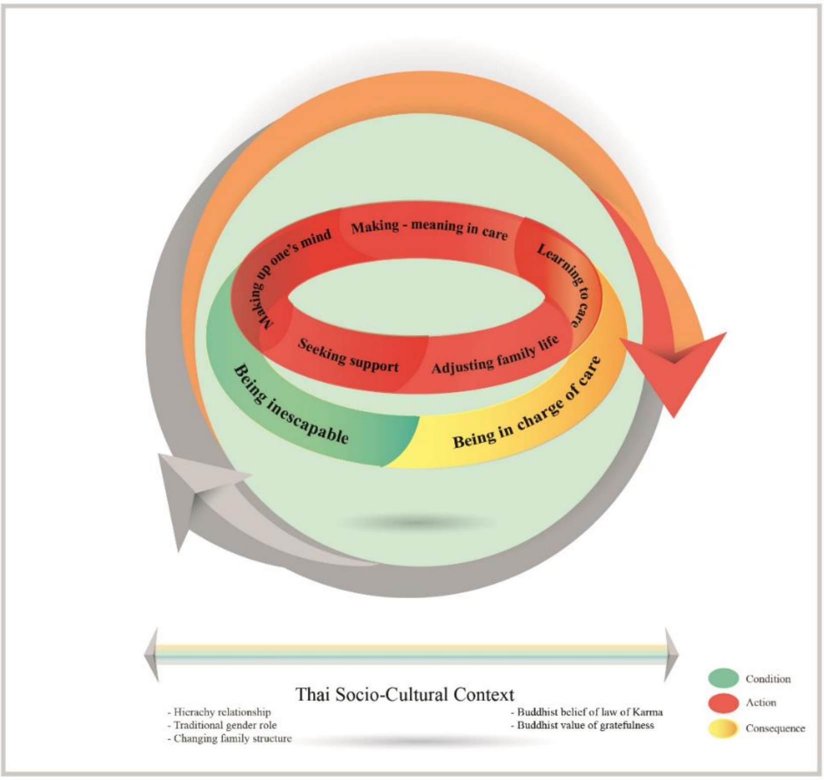

Figure 4.3. Model of Doing One's Best to Move on

Being Inescapable

Being inescapable represents a condition of the moving on stage. It is a feeling of absolute unwillness to be a caregiver. These participants felt that they have been forced to take this role or it had to be them to do it while their intial feeling is to resist or push back. Participants relectantly agreed to be the caregiver for various reasons: assigned to, lived in the same household as the patient, felt lineage, and committed to care. These feelings of inescapable is a condition that pushes the participant into qustioning the caregiving role. In this stage, the participant was still searching for the meaning in care now combined with feelings of being inescapable. In addition, participants realized that patients who were clinically stable would, indeed, return home. They also believed that if no one took care of the patient, the patient would die. These participants felt they did not have a choice as death was the other option. The inescapable statement by participants supported why they had to provide care for these patients with HMV. It was *inevitable.* As Bunnak who provided care for his loved mother with ventilator at home said:

> There would be no choice if there were no one. She (patient) would not survive…so…I decided to bring her back to my home. If it were others, they would not do it. …because they didn't have bonding…or deep attachment much. (Bunnak)

Other participants expressed that they *were assigned* to be caregivers by other family members. The following reasons were: unemployed, non-permanent employee (agriculturalist), lived in the same house, lineage, and commitment to care. Three participants, who were unemployed and lived in the patient's house, were assigned to be primary caregivers. They said that other members could not take care for the patient, because they lived away from the patient's home or had jobs. As they described:

> Nobody else is available. My sister is working in Sa-Dao (a district of Songkhla and far from participant's house), and my mother is afraid to carry out care procedures, especially, cleaning the tracheal stoma. She has never done it before. So, every morning it's my duty to clean it and take care of him. (Banchuen)
>
> My mother assigned me to take care my brother (patient), because I stay at home all day. My uncle sometimes comes to help. Meanwhile, Pia (Patient's wife) is too busy with her work. She is selling things all day at the market and also must take care of her two-year old daughter. I'm not busy so it must be me. (Pradoo)
>
> It must be a person who lives near the patient's house. Someone who lives far away cannot come here to help us. I understand the rationale and, therefore, accept it. (Jampa)

Additionally, a daughter, particularly the youngest daughter, of the patient was offered as reasoning for assignment the caregiver role by other family members. Two participants, Lamduan and Mali stated that they must demonstrate the caregiving role because other children were exemption for this criterion. Participants perceived that it would be very difficult for their older sisters to grasp complex care procedures such as suctioning, ventilator maintenance, and cleaning tracheostomy tube. They concluded that there was no option or escape for them. They eventually had to accept this role, they said:

> My mom (patient) has got three children as two were men and one as me was woman. It must be me exactly because I'm a daughter. (Lamduan)
>
> Other siblings are very old and had a bad eyesight. Some persons have to wear glasses and take a long time to insert the suction catheter into the tracheotomy tube for suctioning. They do the care procedures too slow. I'm the youngest and I can do the procedures better and faster. It is the duty of the youngest daughter. (Mali)

The participant also noted feelings of *lineage* with the patient - mother, father, sibling, uncle or another relative that by default obligated the participant to the role of the caregiver. They expressed that they must care for the patient as their upmost responsibility sacrifice even though not their desire. Some explained:

> Acually, he's only my family relative… his (patient) brother own house but it isn't convenience…I don't know, how to manage? …I said that if his (patient) house is not appropriate for a ventilator, He can stay with me. (Kaew)
>
> We are sibling, he's my brother, we are the same blood. (Pradoo)

Moreover, *commitment by* other family members to provide care is valuable as the patient requires a lot of support. One participant, Banchuen who is a sibling of a younger brother with genetic neuro muscular dystrophy needing ventilator support described to her inevitable caregiving role:

> It is a promise with my older sister that as our brother is sick like this, I will not leave him (patient). (Banchuen)

Although the majority of participants (19 participants) saw it as unavoidable to be a caregiver of their loved one with HMV as noted previously, three participants in this study entered to this caregiving journey differently. These participants had experiences of providing care for patients before requiring ventilator support. When visiting the person in the hospital, they were realized that they had to care for their love one with HMV. These participants seemed to be more willingness than those who did not have experiences. Therefore, people who perceived accepting of the caregiver role earlier in the process were further along mentally than those without experience. As Kulab, 70 years old female participant who had previously cared for her mother with a stroke who was bed- ridden for 4 years spoke about willingness without question when her mother finally needed respirator support at home. She described it as their special connection and giving care to her mother was her duty and she was happy to do so. She said:

> I don’t know…I have to do this duty. I have been doing my duty since I moved away from Bangkok. I care for her since my mother was not severe like this. I washed my mom clothes, did everything for her… living together with my mom before I retired from work. …it is a bonding as mother and child…we have to keep taking care of her for long…it is the way…we cannot think in other ways because we are one… our family…our parent…(we) have to take care of them. (Kulab)
>
> It was my reward to care for my mom because she has provided care to me since I was baby. I have to do… I think that hugging my mom when she is alive is better than hugging her bones after death. Taking care of her is a way of saying thanks. (Kulab)

Pikul, another participant of whose father was diagnosed with an ischemic stroke, paralysis and needing ventilator support stated she was willingness to be the caregiver of her father because she has only one father and cannot find a new one. She said:

> I have to do that…I have to accept it certainly. Where would we find someone like my father? No…We have the only one father. The only one father and only one mother…That’s it. I am happy to care for them. (Pikul)

Payom, 24-year-old female participant who cared for her ventilated father (Guillain Barre Syndrome and muscular paralysis) indicated that she never had a question or denied caring for the patient (father) even with a complex illness. She perceived only that her father gave her life and took care of her since birth so she never viewed this as a burden or problem. Her only focus was that the father must recover and achieve a higher quality of life. She spoke:

> That's my father. I thought in this way since I decided to quit the job when my dad got sick. …only one word in my mind was that my father is only one, and I can't find another one anymore. From that, I am not even afraid of dirtiness. He has been suffered like this from difficult breathing. I am not afraid of caregiving tasks. Never thought things would be wasted. Long before I became as I am now, it was because of him. Without him, how could I be? He nurtured, grew, and taught me to be strong. How can I leave the one who made my life? From that day until now I never have thought of him as a burden. Comparing with what he had done to me for the whole life, I just have provided care for him for only two years. But what he had done for me is much more than what I have done. It is imcomparable. (Payom)

Making up One's Mind

Making up one's mind is strategies or actions used to cope with the feeling of inescapabilty in the stage of doing one's best to move on. Participants in this study tried to make up their mind about their loved ones with HMV and their caregiving experiences. This action eased them to accept the caregiving role. The participants tried to *encourage self, see only good things, and letting go.* A mind adjustment was key for the participants to change their behaviors and motivate themselves to move on from being in the midst of a storm and a labyrinth of suffering.

Self-encouragement reflected the way participants improved themselves to keep on caregiving role. Small success in care participants gained each passing day acted as positive reinforcement and inspired them to move forward. The positive reinforcement had an influence on the participants' enhancement of self-esteem. For example, Chaba encouraged herself to provide effective care for her ventilator dependent father at home. She said:

> I think that I am great that I care for him successfully. I feel glad in each day that passed. At bedtime, I look at my dad. We still have dad with us. I think I am great in taking care of my father

> with ventilator support. As human being, we have to encourage ourselves first… before gathering encouragement from other. It should start by we must empower ourselves. (Chaba)

Seeing good things is another strategy to make up participants' mind when providing care for their loved ones with HMV. Participants reshaped their own views towards caregiving experiences. Seeing good things happen also helped the participants accept their caregiving role more easily. Participants who engaged in strategy concluded that giving patient care was not such a bad thing. Participants found positive expereinces in providing care, such as keeping family activities going, having time for themselves at home and taking care of the patient at home was 'beautiful'. The following examples demonstrate some positive views about caregiving for their loved ones. Two participants, Chaba and Mali stated:

> At least my father (patient) is now at home. The family can buy some food to eat together. We can also meet other family members… Staying at home has many advantages. Some relatives who cannot visit him at the hospital, can now visit him at home. My dad can remember their voices. I think it might be good for him, communicate with relatives. Mom is no longer lonely as well. (Chaba)

> In the hospital, I couldn't sleep. I lost weight and I felt tired. When we went back home, I felt better than being in the hospital, I could eat, drink, and watch TV…I think I could rest more. What ever I did I feel more comfortable. (Mali)

Another participant elaborated further on positive views of caregiving at home:

> Being at home with him (patient) is better than staying in the hospital. Other relatives can easily come to visit… I think encouragement is importance. Everyone tries to cheer him (patient) up… It was difficult being in the hospital for other relatives to come vistit. At home, they can come at any time. (Kaew)

These good things in caregiving that made participants feel more comfortable in accepting their role of caregiving. On the other hand, people who had difficulty seeing positive aspects of caregiving tended to feel more overwhelmed and perceived more suffering.

Letting go was releasing participants' bad feelings as the role of caregiver for a patient with HMV. Caregiving experiences were sometimes a very emotional due to physical exhaustion and a sense of incompetence. They also suffer to see their loved one with worsening symptoms: difficult breathing, secretion obstruction, fever, and pain. They could not help to minimize progressive symptoms. The participant's greatest fear was for the patient to suddenly stop breathing and death. Participants felt overwhelmed with emotional distress like being in the midst of a storm and a labyrinth of suffering. In order to move on in the caregiving role, it was important for the participants to let go of negativism and stigma. In this stage, participants agreed on the cycle of life: birth, aging, sickness, and death. No one is immune to this order. Thus, letting go constitutes making up their mind to accept more of the caregiving role for their loved one with HMV. Two participants explained:

> Must get over it! Need to accept the situation. It's a normal. Nobody escapes from sickness and death… Take it easy and accept the situation as it is now. (Champee)
>
> Living a life is as if round rule…it is there as cycle. Hard to delete it all each day. …I mean when I go to bed, I will know think back…just let go all things. If we think about it, it would discourage us. So, cut it out. (Chaba)

Making-Meaning in Care

Besides making up their mind, participants attempted to make meaning as reasons for giving care in this stage. They were trying to connect the caregiving experiences to themselves. Participants examined the origin of their relationship with the patient. The participants recognized their caregiving role through observations and self-reflection. This new perspective can change their caregiving experience and reduce the overwhelming feeling of suffering and unwillingness. Participants commonly had neutral or pessimistic views about their caregiving role mostly depending on family relationships, bondings, socio-cultural context, and religious belife. Three meanings of care were described by the participants: *sense of duty, Tob-tan Bun-Khun, and Bun-Bab.*

Sense of duty is the feeling of responsibility and commitment which one owes to someone else. The most of participants had parent-child relationships. Participants, consequently, had to take care of their parents even with something so complex and difficult as ventilation at home and serious illness. Some participants who have been caring for their parents with HMV stated that it is a Thai norm of social responsible behavior toward one's parents. It is a responsibility and duty of the adult child to perform specific tasks for an ill parent. The one who performs and take a duty and responsibility is valued as a good person. They also expressed that giving parental care was face-saving (avoid blame from other people). They spoke:

> Because…she's my mother (reply immediately and some tears welled up in his eyes) …The reason that I learned to care is because of my mother. It is a duty…the thing that we must do…Taking care of dad and mom is the thing that we must do to make life go on. It is a duty that is on-going. For me, neglecting care is not an option. (Mhok)

> I must care for him (patient) even though I felt tired. It was my duty. As they are our parent, we must take care of father… because I'm his child …yes…providing for him is burden…such a heavy burden, but it is needed to be. Because he's my father, not others. (Chongko)

In addition, traditional gender roles as a *female role* created a strong sense of duty in Thai culture revealed by female participants. For example, Kalong, female participant who cared for her husband, diagnosed with spinal cord compression and needing ventilator support to prolong life expressed her perspective. She perceived that her husband is like a father, because they have lived and shared both happy and sad times together. It was her duty to be the caregiver. Thus, she expressed her feeling:

> I had never a thought to leave him… I never feel or think like this… because it is my duty. A husband is like a father. Until we get to this point, we had faced many difficult situations together. Although I feel tired of taking care of him, I felt *'Sabaijai'* - comfortable to provide care. (Kalong)

Tob-Tan Bun-Khun (Gratitude). Tob-Tan Bun-Khun was repayment and gratitude from feeling thankful to feeling obligated that to do something in return. Family caregivers created meaning in care as paying back in good turn to their patient. Participants indicated that providing care to their relative with HMV was a difficult and painful situation; however, they had to do because it meant a *Tob-Tan Bun-Khun*. Participants also described that denial or neglect in giving parental care equates to bad things will be happen in their life. For example, the children participants of the patient indicated that they have to reciprocate care to their parents and cannot neglect the responsibility even when faced with many obstacles. They described:

> I cannot leave her. She has taken care of me when I was a baby (tears form in her eyes). Now, she is sick and it's my turn to take care of her… Caring for my mom is a way that I can return my appreciation for her taking care of me when I was a baby. It's my job to do. (Champa)
>
> She's been taking care of me with much love (Tears crowded in her eyes). It's my turn now. (Lamduan)
>
> It's the subconscious mind to care for parents who give birth to me. I feel a strong sens of gratitude that I am able to do. This's shows my awareness of '*Bun-Khun'* as gratitude … I felt *'sabaijai'* (comfortable) at least I won't be blamed from people in society as a bad person. (Bunnak)

Another participant expressed that the idea of providing care for her loved one was *Tob-Tan Bun-Khun.* Fuengfah, a wife of the patient (unconsciousness and in a coma) also stated that providing care is her gratitude and recompensation to her husband. She said:

> I think at least I can provide care for him. When he was healthy, he had given me everything. He had great responsibility to family. It was very good to have him as our family leader. Now, I've to provide care for him as it is my turn. (Fuengfah)

Bun-Bab (merit and sin). Caring of family member who is vulnerable is a value and a virtue and can be traced to religious beliefs in Buddhism, the dominant religion in Thailand. The concept of Karma relates to the law of action and reaction - taking care of family vulnerability is considered to be a way of making good karma, *Bun*. It is also believed that respect and obedience to family members are meritorious and honorable. Conversely, neglecting duties of family vulnerable is *'Bap'* - guilt and bad behavior will cause terrible things to happen to the participant in the further. Those participants who provided care for their patient with HMV stated their beliefs in the law of Karma. They said:

> Um… Regarding Buddhism, caring for mom is a *'Tam-Bun'* (making-merit) or reduce *'Bap'* (sin). People who are born into a family (parent-child, siblings, etc,) has the opportunity to accumulate either merit or sin. In present life, caring for their mother is adding more *'Tam-Bun'*, and reducing *'Bap'* that is carried over to the next life…That is Buddhism… My mom has given me a chance for *Tam-Bun*. (Bunnak)
>
> If I do not take care of my mom, one day in the future I will be like her and will get sick, and no one will help me. I believe in the law of Karma. If we don't help each other now, bad actions lead to bad karma. (Bunnak)
>
> When someone comes to my home, I usually say it's merit taking care of my father (patient). I am willing to care and be happy doing it.… if I did bad for him, it would make me feel bad and would impact my future Karma. I shouldn't have done it. In Thai society, *'Bap'* is a sin, if I do bad things to my parents. This would be *'Bab'*. (Chaba)

Learning to Care

Learning to care was a needed strategy for successful caregiving. Caring for a patient with HMV is difficult and requires many procedures to perfect - usually solo. In this stage, participants acquired knowledge and skills to help them provide care to their loved one with HMV. As they were first-hand caregiver of patients with technological dependent. Four learning strategies were: *observing, practising and receiving feedback, seeking essential information and guidance, and trial and error*.

Observing. To be success in care, participants had tounderstand technological related care procedures and be sensitive to abnormal or unusal situations of both patients' health and ventilator devices. The participant revealed that procedures such as suctioning, tracheostomy care, and changing ventilator circuit were complicated. They had to observe how nurses performed several times. In addition, observing how the ventilator functions, listening to both machine and patient, and receiving patient feedback about abnormal breathing were critical. Two participants, Banchuen and Mali who cared for their loved one with HMV expressed their learning to care observations:

> I never did it before - just watched. When I observed the nurses and patient, I learn from them. When I saw it, I learned more…I watched and learned from the nurses when they were giving care. I always watched. (Banchuen)
>
> I watched and observed how the hospital staffs cared for my mother. What did they do? I observed and asked them … when we came back home, I couldn't leave her. I observed and kept watching…I observed the ventilator alarm. I also asked my mom about her abnormal breathing… Is the ventilator working? Is your breathing OK? Kept asking all the time. (Mali)

Practising and receiving feedback is another strategy of learning to care. Participants valued it as an important way of learning. Participants stated that caring for patient with HMV was much harder than other patient groups. Practising care procedures were important for the caregivers. They recognized that a lot of practice and feedback from the ventilator nurse were vital. Performing care procedures by themselves, improving self-confidence and comfort with complex care and being away from the hospital were obstacles to overcome. Four participants explained their experiences:

> I have to do what nurses demonstrate. I should be able to interact with nurses when they gave feedback, asked the questions. I can answer, something likes that…it helps me gain more confidence. It's better and better. If we don't have confidence or are afaid, we would become stress and anxious, right? But if we have a confidence, we will be fine. (Kulab)
>
> Although I never done (giving care) it before, I learned from the hospital nurse. She told me to observe her at first and then I must practice feeding, suctioning, would dressing etc. (Pikul)
>
> I must do it, it was needed… must do what the nurse taught me because my brother is coming back home on the machine. I have to do it. (Banchuen)

Seeking essential information and guidance. Participants attempted to learn caring procedures in the hospital from the healthcare providers. In addition, social media resources by listening to the radio, watching TV, and searching the internet were helpful in learning more to be a caregiver of a patient with HMV. In addition, the participants gained knowledge from other caregivers who had previous experience of giving patient care. As a result, the participants felt a greater understanding about the patient and their caregiver role. Some participants stated:

> I gained lots of useful information from listening to the radio, watching TV and searching the internet… Information from the internet was very helpful. (Payom)
>
> Learned by asking other patient caregivers who were facing the same patient conditions in the hospital… Asked others for information who had patient care experience using the ventilator… I learned from using the equipment so I will share my experiences with other people who will use the equipment in the future. (Chaba)

Additionally, the participants mentioned that receiving explaination and teaching from nurses helped them learn about the patient and the machine. For example, they learned about tracheostomy care, suctioning, general care; turn position, feeding, and hygiene care. Both participants stated:

> The nurse in the hospital advised us on how to take care. We must practice, while being in the hospital. The nurse taught us how to suction and dress the wound. They told us everything. Advised us on how to take care of the patient…Nurses practiced with me about using the tracheostomy tube. How to use the machine at home? How to dress the wound on the neck? (Champee)
>
> They taught us how to care for and clean the patient. They also taught us how to suction, cleaning, hand washing and everything. We are caregivers similar to nurses at Hat-Yai Hospital. They taught how to care for the patient every day. It was starting with suctioning, feeding, and feeding tube. How should we care for

> the patient? How to change and provide cleanliness. The important thing is the bedridden patient who has pressured ulcers. They (nurses) also taught how to turn position and move the patient. (Payom)

Koon, other participant clearly supported how the nurses taught and trained him on the ventilator and how to handle patient problems at home. Koon stated:

> The nurse said to me that she will teach me how to use a self-plating bag. She said that if the ventilator machine is not working, I must perform manually with self-plating bag…They taught us how to use this machine… Pour the water. Don’t let the water surpass the line. Don’t let the water run dry. We must care for the machine carefully as well. (Koon)

Trial and error. Participants defined trial and error as trying various techniques and technologies to provide care for their loved one. The participants learned from their mistakes in crisis situations. This crisis situations created a feeling of uncertainty and made them feel very frustrated. In managing the home ventilator, participants had to perform many procedures: aware of power outages, adjust ventilator settings, handle ventilator failures, and weaning. These were significant behaviors that could lead to sudden death or further deterioration. Mali, female participant had to adjust the ventilator pressure to fit patient’s breathing by trial and error. Without a clear understanding, Mali was just following the procedures that she observed in the hospital. She said:

> I saw the doctor adjust it in the hospital. The doctor would increase pressure from 20 to 25 and then from 25 down to 20. So, I adjusted it like the doctor did. I observed and adjusted it. I didn’t change it more than the doctor did…Actually, I don’t know what it means, what’s IPAP. I don’t know. I just know that if the patient is tired, I will increase pressure. When her

> symptoms reduce, I will decrease it to original… I will adjust it to fit her condition at home and to make her (patient) less tired and get better. (Mali)

Kaew, male participant who is an uncle of a young adult patient dependent on HMV (myasthenia gravis and respiratory muscle weakness) spoke of how to wean the patient off the machine. He tried to encourage and motivate the patient to wean off the machine. In addition, he did trial and error by increasing the number of hours of weaning until he found that the patient could breathe by himself without the machine. Kaew explained his experience:

> Usually, Prapat (patient) wasn't allowed to be taken off the ventilator machine. I spoke to him that he should try to wean off of it… I tried to increase the number of hours for weaning from 2 to 8, 10, 17, and finally 18 hours each day… Early period of weaning he felt tired; however, he could breathe on his own and did not want to be dependent on a machine …He also worried that he couldn't breathe when sleeping so he used the machine at night. I observed at that time until he felt confident he could breathe by himself. Soon he was taken off the machine all the time and can now breathe by himself. (Kaew)

In addition, two participants in this study expressed their trial and error experiences in caregiving techniques. They changed or adapted to the patient's needs in order to reduce symptoms and costs. They said:

> If dad (patient) cannot eat that's a problem. It is difficult for him to digest high volume food. I have to try to reduce it to less than three hundred milliliters… Have to try experiments all the time. Before, dad used to take only milk (patient's food). Never had added vegetables or pumpkin. But, Pee-Jib (nurse) said that we can add them. I must put pumpkin and eggs into a blender. So, I tried it. Ah! Have something new. Let us learn… I used to use pampers as pads. Now I use a plastic bag. With a plastic bag, It's cheaper. The bag is only ten baht per pack. I have replaced with the new bags. I just wiped and clean for him and change the new bag. That's it; we can adjust. (Chaba)

> I made a sling for her to exercise, to increase muscle strength… and set cans beside her bed to call the caregiver. She can now communicate so no need to pay someone. (Champa)

Adjusting Family Life

Caring for the loved one with HMV was time consuming. Participants spent almost 24 hours a day in caregiving. Beside, they also had other roles to take in family. Participants shared their experiences of having family roles such as a job, housework, spousal time, and caring for other family members in addition to caregiving duties. The competing demands challenged participants to adjust their family life in order to move on. The participant perveived that without adjusting family life they could not success in providing care for their love one with HMV. Therefore, they tried their best. The participants had to integrate other family members into the participant-patient relationship. Will other family members feel relaxed, content, and stress-free? Participants hope family members can remain even keel, feel safe, appreciated, engaged and fulfilled. However, they perceive the difficulty of trying to balance a normal family life with the obstacles and challenges of providing care for a loved one at home. As Chaba's and Chongko's description, it was the challenges trying to meet the needs of both patients and all other family members. Schedules and lifestyles were adjusted to fit patient care activities such as waking and sleeping times, sleeping at the patient's bedside, and always having dinner at home rather than out. They explained:

> I had to adjust everything. I never could wake up late on holidays as I have children to attend to. I had to wake up at 6:00 am to boil water and prepare milk for my father (patient). Then I had to sponge bathe him and change his clothes and linen… I would like to take my children out to eat, but we always had to bring it

> back home to eat. Since my father sleeps downstairs, I couldn't sleep upstairs with my husband. Family life was full of adjustments. (Chaba)
>
> I had to adjust my life to many people lives. I had to manage time for my husband ... What does he want to eat? Do you want go to the market? Do you want to buy some food together? I had to balance caring for my husband's needs with looking after my father. My husband thought that looking after my bedridden father, and taking care of the children was honorable for me. (Chaba)
>
> I tried to do my best taking care of every one as the same time, children, husband, mom, sister, and the patient. I tried to manage even though I have never done before. (Chongko)

Seeking Support

Participants looked for information or resources to help caregivers move on in the midst of a storm and a labyrinth of suffering. As family caregivers for ventilated patients at home, they had to face a lot of new responsibilities, many of which were unfamiliar and life-threatening. Additionally, essential medical devices and other instruments to sustain life were required. In the beginning, they felt overwhelmed and alone. The participants attempted to finds a lot of things they can do to make the caregiving process easier or more pleasurable. Seeking and getting support they need can benefit everyone. The participants revealed several sources support including *health care institution, nurse case manager, other family members, and Sub-District Administration Organization.*

A healthcare institution is an organization of people, institutions, and resources that deliver health care services to meet the health needs of target populations. Most participants had very limited financial means. Medical devices and supplies from the healthcare system were vital such as ventilator, mobile oxygenator, and suctioning machine. Participants who had received support revealed that some medical instruments were either borrowed at a very low price. Disposable medical supplies were also supplied by the hospital included suctioning tube, gauze, cotton dressing, nasal-gastric feeding tube, and sterile water for the ventilator. They expressed:

> The hospital provided many material supplies. I paid for some and got some free. My son (patient) was lucky when the nurse came to visit at home as they also brought some dietary supplements for him. (Saiyhud)
>
> I receive materials and supplies every 3 months. When I came to the hospital for our doctor appointment, I told them what we wanted such as suction catheters, sterile water, and gauze. It was a limited number that was available. However, each week I can get them at the community health center at a reduced cost.… The hospital also provides some machines. It helps me a lot to provide care for my dad (patient) as well as giving me encouragement. (Chaba)

Nurse case manager of HMV who came to visit the ventilated patient and family caregiver at home was crucial for sustaining care. Providing service when the patient is discharged from the hospital via hospital network centers in local areas close by are importance. In case of emergencies, local nurses could visit the patient immediately, provide treatment and care, and follow up on the accuracy of care provided by family members. Emergency calling was also always available for the participants. Some caregivers asked for suggestions from the nurse case manager when having problems or dealing with harmful situations. Payom, young female participant expressed that this is a benefit for both caregiver and the patient who has serious illness. She stated:

> When my father (patient) returned home, I was worried that I couldn’t give him the same care that he received in the hospital. The nurse said to me that they will not leave me alone. A few days later, they came to visit and gave me some suggestions.

> They also collaborated with the hospital network center in my local area close to my house in case of an emergency. (Payom)

As Chaba and Champee, explained their experience calling nurses to consult about ventilator failure and worsening symptoms of their patients. They stated:

> When the electricity shut off after few months of providing care, I lost my mind. So, I called Pee-Jip, nurse and asked her "What do I do without electricity? Pee- Jib said " Check with Metropolitan Electricity Authority about blackout and tell them you have a patient dependent on a respirator and you must let them (MEA team) know. Then you must manually support with a self-platting bag" It calmed my nerves. (Chaba)
>
> Yesterday I called the nurse at Hat-Yai hospital. The ventilator was too loud. Can't stop alarm. They told me how to handle it. It will disappear…I was so happy they responsed my phone call. The ventilator was loud with the alarm, but I was amazed that someone answered my call. I'm happy that they told me the problem, and how to solve it. (Champee)

Other family members. Participants also sought support from other family members such as relatives of the patient including children, spouse, sibling, uncle, and son in law, etc. Often, they are living in the same house of the patient. Participants indicated that support from other family members was beneficial. This helped with moving on from being in the midst of a sorm and a labyrinth of suffering. Participants felt that although they are the primary caregiver, they cannot do everything on their own (24 hours of providing care). They needed help from other family members. The type of support from other family members including secondary caregiver, house working, decision making, and cost of care support. These types of support made them feel relaxed and reduced their stress. Without the support they need, stress quicky compromises their ability to provide care.

> If I felt tired, I would like to go outside to relax. My two sisters came to replace me and take care of my mom (patient). I once left for five days. Rotation was important. It felt like mental health therapy. (Kulab)

> My other siblings come to help me and even consult when something bad happen. "How do I do?" This makes me feels warm, I can consult them about what I want to decide about the patient. This is better than being alone…The other sister who is not a caregiver does, though, help me we laundry or the housework. (Mali)

> My siblings give money to support. They pay the cost of milk, pampers or other items. My older brother in Bangkok also sends money for me… The relatives will help by giving me money to pay for patient food, pampers, and other items. (Chaba)

> Our family is united. Everyone is available to provide care for my father because they live not too far from my house, easy to come when they're on duty to take care… Although they can't provide all the time, it allows the primary caregiver to take a break and do other duties. …Some relatives who still come to socialize. It creates a warm feeling. (Pikul)

For the married participants, understanding and support from their spouses was important to the caregiver's psycho-emotional and spiritual components. Some indicated:

> It's important. I live with him (husband); yet, he never understands me. He (husbans) did not take care of my parents. It is terrible. But behind the scenes, my husband is proud of me. He tells his friends that I can do everything for caring dad. (Chaba)

> My husband is good. He takes care of my dad. I think he does it better than me. He also helps in housework such as cleaning and preparing food for other family members. I think he helps a lot. He doesn't want me to get stressed. He tries to reduce my stress level (Chongko).

Sub-District Administration Organization is a local governmental unit that can provides emergency ambulances to transfer the patient from home to hospital. This was important for those who live in rural areas far from the hospital. Participants in this study said that the Sub-District Administration Organization is a free service. The ambulance was always prepared to transfer. It provided essential medical devices such as oxygen tank, self-inflating bag, and mobile suctioning. It was also convenient, responsive, and available 24 hours a day. Mali and Champa expressed their support for the Sub-District Administration Organization. They noted:

> I think the emergency car of the Sub-District Administrative Organization is good. When we need to go to the hospital, I call and tell them that the patient is bedridden and on ventilator. They will come… There are many centers to choose from. I can call anywhere and anytime. (Mali)
>
> The emergency car of the Sub-District Administrative Organization operates like an emergency and rescue ambulance. The emergency car has a lot of space and equipment. Taking a private vehicle is impossible to do. (Champa)

Being in Charge of Care

Being in charge of care is the consequence and the end of this stage, doing one's best to move on. Being in charge of care was defined as the participant's feeling confident and being able to perform the caregiving tasks effectively. It also gave them a sense of confident as they were able to meet the patient's caring needs. Participants mentioned that caring for their loved one with HMV that their ability to manage both patient's daily living and handling the ventilator at home. The participant's managment of patient's daily activities included: bathing, bedding, grooming, cleaning, toiletry, feeding, mobility, transportation, financial management, and house chores. The participants revealed that attentiveness to the patient's daily activities was the key. Their attentiveness would help them notice abnormal things happening with their patient. Some said:

> I felt confident to take care of my dad (patient), no fear. I could do everything for him…All things that I do for him even cut his toe nails. I cleaned every nook and cranny of his body. I felt like his body is mine… I might not have seen red spots or other abnormalities on his skin. The patient couldn't speak and was blind. (Chaba)
>
> At the beginning, I felt burdened psychologically. Later on I get used to it. …like it is my duty…then I got less stress. I have taken care of my mom for a long time, and think that giving care has become easy. After I wake up in the morning, I provide bed bath, change a diaper, clean the tracheostomy wound, suction, and give an inhaler drug by nebulizer. Then I make food, crushing oral medicine, and feed her. After caring for mom, I then take care of my little child, cook for other members, and sometimes go to supermarket to buy things for my husband…At noon, I clean her body, suction, and feed her. In the evening, I changed her diapers again, suction, and give the bronchodilator by nebulizer. I know that bronchodilator has tub tested two time per day meanwhile tracheal suctioning every time before feeding. (Lamduan)

As handling ventilator care at home, those participants who had been taking care of patients with HMV for several months or years, they perceived the ventilator is a part of their daily life. These participants were able to monitor the ventilator functions and see if it was working properly. Accuracy and safety were also important considerations. These ventilators related caregiving tasks includeding care of tracheostomy tube, suctioning, giving bronchodilation medicine, emergency care when needed, and problem-solving. Chaba, Mali, and Banchuen explained their experience with handling with HMV as familiar and they known how to handle it. They supposed:

> Previously, I felt uncomfortable to hear the ventilator sound and couldn't sleep. Right now, the machine is a part of my life that I am familiar with the sound. If I don't hear it, something is wrong. (Chaba)

> I felt familiar with the alarm sound. I knew what it meant, my mother (patient) might have a secretion obstruction. When faced with her problems, I knew how to solve them. I can't explain why I could do it as automatically. For example, meanwhile I was suctioning and I found that she (patient) breathes faster, I used the rescue bag on one hand and other hand used for suctioning. Previously, I couldn't do this. I can now do everything for my mom (patient), no fear, no worry. I feel confident. (Mali)

> I feel confident to take care of him (patient). Previously, electricity stopped working and the ventilator stopped working. My brother told me that he was tired. I immediately used the rescue bag to support his breathing… I ready knew how to clean the tracheostomy wound and how to change the ventilator circuit. (Banchuen)

However, some caregivers who could not move on or struggle they were stop in this stage. Returning to the prior stage of being in the mist of a storm usually appear and they still have felt in sens of sufferings and sadness. Consequently, it might be influence to quality of care and well-being both patient and caregiver. While, the caregivers who could get through the process they have obtained to further stage, achieving blissfulness of mind.

Categories 3: Achieving Blissfulness of Mind

The final stage was achieving blissfulness of mind. Participants who became incharge in care would move from the stage of doing their best to move on and reach this final stage of caregiving journey. A sense of blissfulness consequently emerged when the participants had a feeling of confidence and the ability to manage the caregiving role for their loved one with HMV. Being in total charge of maintaining daily care and mastering the ventilator were cited. Participants defined a state of bliss as listening to the voices in their hearts. Participants further defined achieving blissfulness as feelings of joy, self-fulfillment, and a deep satisfaction that cannot be achieved in any other way. Four sub-categories of blissfulness stage included: *a sense of pride, realizing meaning in care, providing humanized care, and living life in balance.* The achieving blissfulness of mind model presented in Figure 4.4.

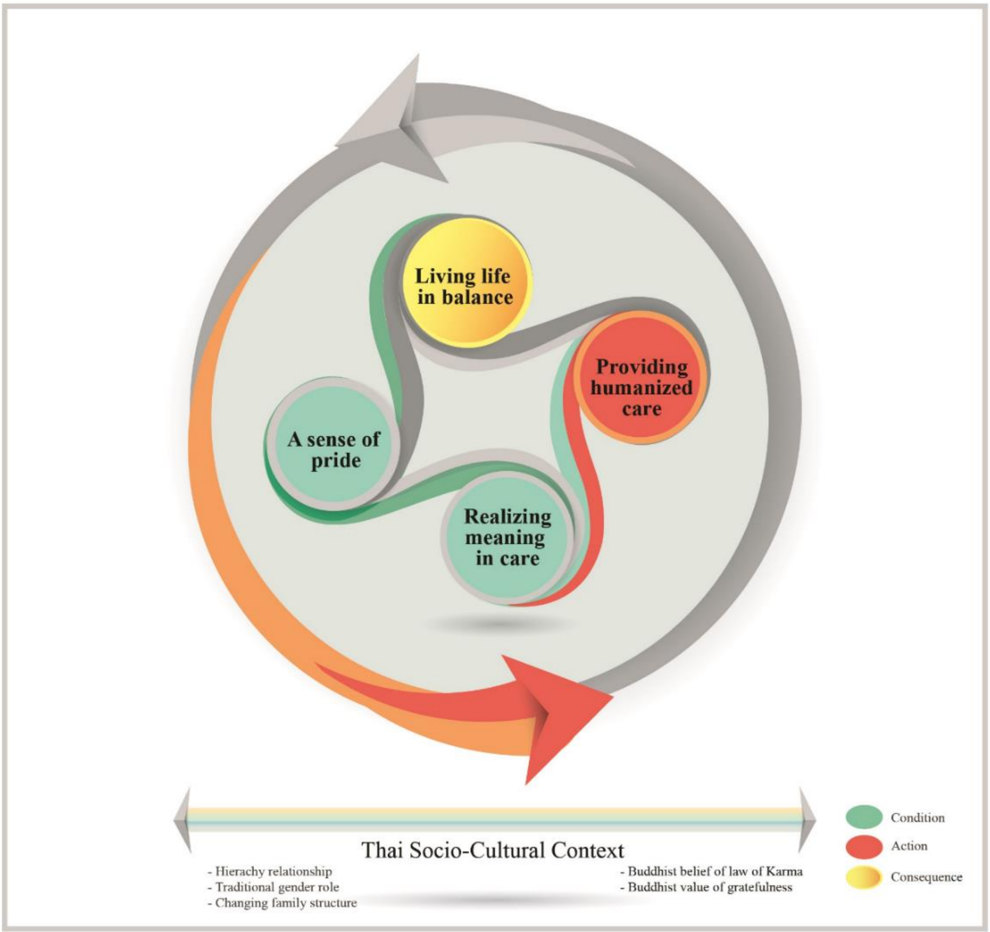

Figure 4.4. Model of Achieving Blissfulness of Mind

Sense of Pride

Narratives from participants revealed that those to reach the blissful stage were proud of himself or herself in their caregiving role. Participants had a felt pride in having the opportunity to care for their parents (relative) even though they have little or no experience. They provided the best choice on the personal level as well as doing what is considered right by society. They also felt appreciated by many people in their community that they are role models for young members as a good person who provide care for the parents. As Bunnak described his recognition of sense of pride. He stated:

> Other people in community may think that I'm a good person taking care and never abandoning my parents. At least, I put all my capacities and efforts to do my best. …People would say to me like *'Tok-Nam-Mai-Lhai, Tok-Fai-Mai-Mhai'* (Fall in the water, not get washed away. Fall in the fire, not get burnt' to them). They would acknowledge me as good person, and I have earned gratitude and respect from them. (Bunnak)

Another participant, Champee and Chaba spoke of a sense of pride when teaching other caregivers how to care.

> On occasion, I have helped care for some of my neighbors who were bedridden with illness. I have suggested to their family members about care procedures…My suggestions about wound care and other things lead to their decision in not taking their loved one to the hospital. I felt proud that I could tell them how to do it. (Champee)

> Everyone who came to visit at my home said that my dad (patient) is well taken care of. They admired me for doing good deeds and said I serve as a role model for their children. Even though I have low level of education, I could still take care of him. I felt proud. I can feel proud that I can take care of my father although I have never studied about nursing… My negativity changed to happiness… Caring for my father was not only hard work, but it instilled a feeling of happiness in me. (Chaba)

In addition, a sense of pride occurred when participants saw improvement of patients' health conditions. Two female participants, Chaba and Pikul expressed their feelings about sense of pride in their caregiving. They said:

> I never thought that my dad (patient) will be with us and dependent on a respirator. I had an earlier idea that when a person gets sick, they will die…this is the new experience for me, and I feel lucky. Now, my dad has gotten better after a six-month illness. I felt proud. I have nothing to give him except this care… Since I have taken care of him (patient), I have never seen a pressure ulcer. Everything has been done well, and I think that is my success. (Chaba)
>
> I felt good when saw my father (patient) get better from his illness. Many people who came to visit him at home also said that he looked better than he did before he got ill. (Pikul)

For some patients who completely recoverd, removed ventilator and breathed by himself, for instance the participant spoke of his successful caregiving that is their sense of pride:

> Honestly. I think this is a success. Previously, many people said that he (patient) was going to be bedridden and will need the machine forever. However, after seven months he (patient) didn't want or need the ventilator. He looked like he did prior to his illness. (Kaew)

With a ventilated patient in their end stage of life, the participants felt these patients should be made comfortably as possible. They also expressed their sense of pride when providing as best care as possible in the last moment of the patient's life. Participans saw promoting a peaceful death as part of their caregiving role. Kulab, female participant who cared for her mother with ischemic stroke, unconscious, and dependent on HMV viewed the end stage of life with a perceived sense of pride. She saw that giving care to her mother in the last moment of life was equivalent to receiving a life-time achievement award.

> It might be difficult to hope that my mom (patient) will get well and can walk and speak again. I only hope she will be happy and become more comfortable with my help. I will care for her until the last day of her life… Every day, I give the best care for her, cleaning, comforting, and hope for no complications. I am happy that I can live with my mom. She and I both feel good.… I feel happy to provide care for her and show her gratitude… it is my happiness and a gift to myself – a life-time achievement award. (Kulab)

Participants in this study perceived that they had done their best care to the loved one, they indicated that they would not feel upset if something bad happeded or death to the patients. Three participants, Pradoo, Fuengfah, and Chaba came to understand and accept the result of caregiving. They said:

> If he (patient) died today, I will not be sorry, because I did my best for him. (Pradoo)
>
> If he (patient) died, I think I will not be sad, because I have cared the best I could for him. (Fuengfah)
>
> As I have taken care my dad, I can see the cycle of life that death is natural… I better understand life and can accept his (patient) death... I will be sad when he dies, but I will not be sorry because I have done my best for him. (Chaba)

Realizing Meaning in Care

As participants had been taking care of their paitents with HMV for some period of time, their experiences led them to the true meaning of caregiving. It was also a condition stage to achieve blissful of their mind. Participants in this study described what it means to have experienced a tremendous. They found that is *legacy of love* when caring for their loved one who need ventilator support at home. They require nothing in return only an act of love and good wishes that the patient continues to be happy and positive outcome. Three of them said:

> Legacy of love (smiling) …it makes me know that although I have nothing, I can take care of him (patient)…that is due to the love we have… Everything that I do for him; it's not only duty but also love …I love him and don't want any money or his heritage, I just want to care for him as best as I can while he's still alive… Right now, I understand the meaning of love and concern. (Chaba)
>
> I do not expect to receive any compensation from the caregiving role. I would like him (patient) to get well, I do everything such as wiping, feeding, and toileting. I give care for him like he was a baby. (Saiyhud)
>
> I wish for her (patient) to have a comfortable living and a high quality of life. I can live unpleasantly if she is comfortable. (Kulab)

Providing Humanized Care

Providing humanized care as holistic action that the participants provide to the love one. Humanized care is defined when participants are recognized for their caregiving role to their loved one with HMV. The participants want their patient to live well and without suffering. Moreover, attentive acts by the participants ensured that their loved one and their needs were at the heart of every decision made. The participants do their best with effort, willingness, and abilities to provide good care. Caring with love goes beyond the technical knowledge and acquired skills. Spiritual and religious beliefs are rooted in the Thai culture and its people. Participants have a deep understanding of humanized care and ability to integrate in their caregiving as a holistic giving care. Providing humanized care includes *a sense of belonging, maintaining conversation, promoting social interaction, and striving for merit-making.*

A sense of belonging is defined as the participant staying close to their patient physically and spiritually in order to observe patient symptoms or breathing problems. The participant made their loved one feel comfortable by physically being nearby. Participants in this study described some strategies they did to make patient feel they be there, close to them such as turning on TV or Thai music (Manohra). Two participant said:

> It's like "I can't go any where, I just stay here." At bedside, it is so specific dependent that I have to be right here. (Mali)
>
> By turning on the TV, it offers companionship…At night, my father listens to music to help him sleep better… (Chaba)

Maintaining conversation is another element of humanized care they provided. Although patients who depend on HMV have varying level of awareness from consciousness to unconsciousness and unresponsiveness, participants conversed with their patient about activities happening or about their caregiving even though they could not speak. Chaba who provided care for her non-verbal and blind HMV father shared her experience as they had conversation. She explained:

> I told my sister that I did not want separate rooms. I wanted him (patient) to hear from other people. I would he felt like someone is talking to him…Yes! He couldn't speak, but he understood. He liked someone to hold his hand. He liked someone sit bedside his bed. If he moved the mouth, he was hungry. After feeding him, he went to sleep …Sometimes I liked to tease him. I said *'Uncle, Are you hungry?* I would also touch his abdomen. He would smile… He liked to listen to sound. He liked his grandchildren to visit and his own children to read fairytales to him. (Chaba)

Kalong and Payom took care of a totally ventilated patient who was conscious and verbal. They mentioned that back and forth conversation allowed the patient and her to have a normal family-like experience. They expressed:

> The patient liked to watch Thai boxing, listen to the country music, and shadow play (Nang-Ta-Lung). I and Wat (son-in-law) sometimes turned on the TV for him. He smiled when happy… I usually asked him *'what kind of food do you want? I will buy it.'* I know that he couldn't eat but I would like him feel like a normal family member. Sometimes I asked him to watch the news and his nephew also asked to watch cartoons. (Kalong)
>
> All family members cracked jokes to make him laugh. We were included him in all family activities. He was treated as a normally family member not as a patient. (Payom)

Promoting social interaction between the patient and family relatives and their friends created positive feelings. Saiyhud, mother of patient with myasthenia gravis and need ventilator support at home described her experience with promoting social interaction that enhanced the patient to a faster than normal recovery. She said:

> I don't know how to say it, but he (patient) got better from his illness. At home, he got a lot of encouragement from his friends and person who come to vistit. I saw that he was happy. His face brightened up when his friends came over. He could talk and felt relaxed… His friends supported and encouraged him to get better. (Saiyhud)

Striving for merit-making is a meritorious and dedicating acts for their patient who could not perform the acts by themselves. All participants were Buddhist. They mentioned merit-making for their loved one and believed that was a way to bring better illness conditions for their patient. As Pikul and Lamduan expressed their experienced of prayed for better conditions for their mother. They strongly believed that praying or chanting from Buddhist monks improved her mother's illness condition and bring a peaceful death. They said:

> After two months at home, her (patient) illness worsened and she had difficulty breathing. I invited the monk from our Buddha temple to make merit for her… merit making, I hope that she either sustains a higher quality of life or enters a peaceful death. (Lamduan)
>
> Previously, I invited a Buddhist monk to come to my home to make merit and pray for my dad (patient). My dad was awake of what was happening and he could make-merit by *'Whai'*. After praying, the monk blessed him to become healthier and to further sustain his life … I made merit for him as well, and I felt much joy. With my dad on the ventilator is why I invited the monk to our home. (Pikul)

Living Life in Balance

Living life in balance is finding a middle ground between the caregiving role and family life. Participant felt familiar caring for ventilator dependent patient at home and strove to live a normal life. Emotional calmness and acceptance of another person's situation helped them restore balance in their life. Three participants stated:

> Right now, everything is normal… I feel normal… I get used to it. I am familiar with care… I have done everything and make it as typical as possible. (Kajohn)
>
> As I have taken care my dad, I can see the cycle of life that death is natural… I better understand life and can accept his (patient) death... I will be sad when he dies, but I will not be sorry because I have done my best for him. (Chaba)
>
> Now, I can do everything comfortably and fit. As if I can go everywhere I want to go. I am not worried, if there is someone we trust to watch her, I will be comfortable. (Mali)

Summary

In this study, it was found that the participant’s perceptions, adjustments, and experiences were embedded in the process of caregiving. The theoretical model explains the participant’s spiritual journey and behaviors of moving on in the process “Thriving in Family Caregiving”. This newly developed explanatory model illustrates the process of the psycho-social interaction of moving through the cheotic and obstracle situation. The process identified three phases: 1) being in the midst of a storm and labyrinth of suffering, 2) doing one’s best to move on, and 3) achieving blissfulness in the mind.

Discussion

The findings from this study revealed that the family caregiving model for their loved ones dependent on a ventilator at home is a complex and dynamic care process. A number of physical, mental and spiritual adjustments occurred in concordance with specific social interactive patterns affecting care. The core category of this experience was *Thriving in Family Caregiving* throughout these many adjustments. Family caregivers described their struggles during efforts to thrive in the role of the family caregiver of a home ventilated patient segwaying to frustration and anger at its imposition on the family's way of life. The study findings also added to a growing body of literature concerning the nature of living with a technology dependent patient at home. This discussion shall begin with participant characteristics. Next, Thriving in Family Caregiving, a major concept that emerged from this study, and categorical findings whether similar or different to previous research will be explained. Finally, how symbolic interactionism and Thai socio-cultural context influenced family caregiving experience shall be presented.

Characteristics of the Participant

The study participants were mainly female which replicates several other studies that the female gender dominates Thai family caregiving (Chaiyarit, 2012; Napa et al., 2017; Wongsawang et al., 2013). This validates the Thai culture regarding traditional gender roles and female accountabilities in taking care of its family members (Ritteeveerakul, 2005; Sasat et al., 2010). Yoddumnem-Attig and Attig (1993) stated that this culture continues to influence female gender roles, particularly among mothers and daughters, who play a major role as primary caregivers in their respective families.

Most of the participants were young, married adult caregivers without any underlying diseases. They possessed at a minimum a primary school level education – Thailand’s mandatory minimum educational requirement. Meanwhile, the relationship between family caregivers and patients with HMV were adult children. This finding was similar to previous studies in Thai family caregivers of their members with psychosis (Napa et al., 2017). One possible explanation may be limited educational opportunities particularly in the rural areas. The participants in this study all lived in rural areas of Songkhla Province. Moreover, Podhisita (2012) and Peek et al. (2016) revealed that recently changes of the Thai family structure from the extended to the nuclear family, the number of family members has been decreasing. The children as young adults have been thrusted into taking care of their elderly parents.

Household income usually derived from the family caregiver’s own work and/or provided by other family members who cannot or would not provide direct care for the patient. This finding reflects the typical situation in Thailand that key family members must be responsible to provide all support whether financial, care procedures, or transportation issues usually to a vulnerable and needy parent or immediate family member (Peek et al., 2016).

Thriving in Family Caregiving

The model of thriving in family caregiving for their loved one with HMV comprises of three categories: being in the midst of a storm and a labyrinth of suffering, doing one’s best to move on, and achieving blissfulness of mind. Each category of the model follows the paradigm of condition, action, and consequence. It should be noted that these components of the process emerging from the data did not replicate any previous model of thriving. These study findings also added to a growing body of literature concerning transformation in family caregiving for their loved one dependent on HMV and the nature of living with a technology dependent patient at home.

Family caregivers’ transformation included recognizing and adjusting their struggles during efforts to sustain giving care for their loved one with HMV, and their impending frustration at their imposition upon the family's way of living. The moving on process of family caregiving illustrated doing their best for integrating technology life support for their care. Achieving blissfulness of mind, the family caregiver had to reconstruct their own thoughts by valuing their own experiences as vital and unique for the patient. The family caregiver transformed from discovering the meaning in care to achieving thriving in care which eventually shaped the caregiver’s ultimate care plan. This principle is due to the fact that the family caregiver recognized that caregiving as a loving, humanistic touch, and desiring the patient to live without any suffering in the latter stage of their life. This process helped family caregivers adjust their own management behaviors style in a way that helped them improve clinical outcomes for their loved one with HMV and to live their own lives more balanced and content.

According to the literature, the universal meaning of thriving is a positive concept that exists as a continuum that individuals grow and develop at different rates and in different ways based on interactions with the environment and the on-going development of self (Haight, Barba, Tesh, & Courts, 2002). Maslow (1954) described the positive outcome as thriving is self-actualization where individuals experience peaks and highs. Theoretical perspectives on thriving agree that thriving implies growth, development, and prosperity, although differences emerge in the specificity of what this growth and prosperity look like, and the context in which it occurs (Bundick, Yeager, King, & Damon, 2010; Diener et al., 2010; Lerner et al., 2010)

Thriving in the family caregiving process for patients with HMV initiated from a caregiver's perception of un-readiness and an unwillingness to achieve blissfulness of mind - the most happiness in both their caregiving role and in life. However, the model is contrary to the willingness model, where willingness before care had been provided as the likelihood of establishing a successful caregiving relationship and could be sustained over time (McDonell, Abell, & Miller, 1991). The model of thriving in family caregiving in this study indicates that although the caregiver felt an unwillingness and a non-accepting role before taking on the caregiving role for a patient with HMV, it could be used to encourage and develop the caregiving role during the initial period of providing care.

Thus these family caregivers had the ability to transform their thoughts to thriving in providing care by changing their attitudes toward providing emotional, physical, and clinical support to their patient. One cause might be the caregiver is very close with the patient igniting compassion, sympathy, and recognizing the fragility of life. These feelings may help shift the mind-set of the caregiver from fear and trepidation to love and kindness (Neff & Dahm, 2015). Therefore, family caregivers can improve and develop to be a competent caregiver and achieve thriving in providing care for patients with HMV even though they initially denied or were unwilling to accept their role.

Consequently, promoting the achievement of thriving in family caregiving is an important first step. Achieving thriving in care enables family caregivers to develop and adjust care patterns continuously. Follow up to problems and patient symptoms improve. The family context and the power of thriving in care enable caregivers to overcome difficulties and obstacles to better serve their home ventilated member. At the moment of achieving thriving in care, the family caregiver moves into a greater conceptual understanding and improved cognitive awareness. They have a deep intellectual understanding of the family caregiver role as caring for their loved one becomes a moral obligation and opens a way for him or her to better understand and find the meaning of life. Another interesting note are the strategies that result in achieving thriving in care by the family caregiver which enables other family members involved in care to help the family caregiver through this transformation.

On the other hand, Thriving in Family Caregiving model was not the same for every participant, adjustments and adaptations were different. In the literature, the thriving theory identifies that nurses who have an understanding of the universal properties of transition are better able to assist these individuals who experience various difficulties (Schumacher & Meleis, 1994; Shaul, 1997). Therefore, this study finding cannot be applied to the process of thriving in care of family caregiver to other patient groups. In general, caregivers were utilized for home ventilation treatment thus, some trends may be similar or neutral regarding achieving blissfulness of mind: a sense of pride, finding meaning in care, providing humanized care, and living life in balance. However, the researchers found that other caregiving categories do not apply to describe other caregiving groups, especially HMV patients. Moreover, the characteristics or identity of caregivers for each group are unique.

Being in the Midst of a Storm and a Labyrinth of Suffering

The initial stage of caregiving for a love one with HMV was perceived as a being in the midst of a storm and a labyrinth of suffering. The family caregivers in this study indicated that providing care lead to feeling overwhelmed, increased suffering and higher stress. The findings have been supported by previous HMV studies that highlighted caregiver stress trying to meet financial costs, negative impact on employment, and insufficient time for oneself/personal relationships (Evans et al., 2012; González et al., 2017; MacIntyre et al., 2016; Nonoyama et al., 2018). Higher levels of stress were also significantly associated with lower levels of quality of life and one’s well-being (Feeley et al., 2014; González et al., 2017).

Caregivers experienced the burden of both working outside the home and providing care for their loved ones at home. These multiple roles and potentially conflicting obligations can cause psycho-emotional stress, more physical health illnesses and an increased risk for caregiver mortality (Falkson et al., 2017; González et al., 2017; Marchese et al., 2008). Family caregivers reported several barriers to care for ventilated patients at home included insufficient funding for paid caregivers, equipment, and care supplies (Dale et al., 2017; Rose et al., 2015). Families required more professional support to create a smoother everyday life adjustment and relieved their ever-increasing burdens (González et al., 2017; Lindahl & Lindblad, 2013). Consequently, the quest for meaning in care emerged. Continuous questions kept repeating themselves: Why do I have to be a caregiver? Why me? Why not other family members? And what is the meaning of care? These feelings and questions initially affected the quality of care provided at home as well as the patient's well-being.

It is unrealistic to expect family caregivers always to be happy to provide care for a HMV family member. With current societal changes in the 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 home to provide financial support for the family (Knodel & Chayovan, 2008; Peek et al., 2016). Providing care for a ventilated patient at home is an inevitable and stressful experience.

Findings from this study represent a key point to obtain for the family caregiver to achieve thriving in care. In this stage, healthcare providers should find strategies or interventions to support and develop family caregivers to enhance their self-confidence and reinforce proper management behaviors. In addition, support care procedures need to be in place when the patient's symptoms worsen or the ventilator malfunctions. An effective and reliable service program via phone calls, on-site service, and emergency home visits must be available and accessible from the get go to ease the caregiver's anxiety and build their confidence in the healthcare support system.

Doing One’s Best to Move on

Doing one’s best to move on starts with the family caregiver’s feeling of inescapability and frustrated to provide care for the family member dependent on HMV. Whether the family caregiver voluntarily enters into the caregiving role or by default, it does not guarantee that they will provide high quality patient care or achieve a successful caregiving experience. Thus caregivers must get through the moving on process to discover two things including find self-encouragement and confidence to do their best to provide care.

In this stage, it can be a turning point for some caregivers who manage to get through doing one’s best to move on; yet, continues to serve only to maintain care. Unfortunately, these caregivers are unable to break through and often return to the sensation of being in the midst of the storm and the labyrinth of suffering. This is very important stage of self-encouragement by their mind and finding meaning in care results in the caregiver developing and mastering their abilities to provide complex and difficult care. Their ability to improve care procedures, reduce clinical symptoms, and extend the life of the patient, results in the feelings of being in control of care and dramatically improving their own self-worth. Thus, healthcare providers should provide intervention to enhance awareness about their perceived and valued experiences in giving care. Health care providers are a key factor in the Thai socio-cultural context.

These findings are consistent to a previous study of Walker, Powers, and Bisconti (2016) for female caregivers of older adults living with a chronic illness. The study findings revealed that achieving coping associated with their caregiving role in term of psycho-social outcomes had less of a burden and more positive aspects. The study suggested it is to understand the context in which family caregiving takes place, including culture, beliefs, and family background. This helps set the stage to work with caregivers to feel more empowered in their caregiving role. Utilization of therapeutic techniques and approaches that promote personal and relational empowerment were also deemed significant.

Achieving Blissfulness of Mind

In The final stage of thriving in family care, the caregiver ready to step to the plate as a willing and able caregiver. It was a positive consequence of taking on the role of the caregiver while some other caregivers who had a negative consequence will return back to the stage of being in the midst of a storm and labyrinth of suffering. The family caregiver would like to live happily without negative consequences from the caregiving role. The caregiver had feelings of joy, self-fulfillment, and the deep sense of satisfaction. In addition, an inner peace and a sense of emotional well-being from giving care to their loved one lead to blissfulness in life. This is also the stage that promotes a sense of pride, provide humanized care, finding meaning in care, and living a balanced life.

Furthermore, realizing meaning in the caregiving helps participants to identify strengths and sources of personal and relational empowerment and the need for culturally competent practice. These findings are consisted with a study of Ayres (2000), caregivers used expectations, explanations, and strategies to interpret their own circumstances in the context of their lives to identify interventions, strategy selections, outcome predictions, and to make sense of events that occurred.

However, in case the caregiver has conflicts with existing positions and beliefs, previous study indicates that social support and religious coping improved positive aspect of individual caregivers (Fitzell & Pakenham, 2010). Therefore, healthcare providers need to be supportive and to facilitate adjustments and modifications. A caregiver's thoughts and perceptions will interpret their experiences in positive and uplifting ways. This supports benefits individuals involved in the caregiving process (Sano et al., 2007; Tang, 2009).

Influenced by Socio-Cultural Context

Not only does culture shape the family caregiving process, cultural beliefs also influence how the family caregiver perceives the patient's symptoms and the technology dependent situation. Regarding symbolic interactionism, human beings act or refer to things as they see them from their perspective (Blumer, 1969). The caregiver's role is a transformational process created through interactions between the family caregiver and their patient and between the dyad and others. Benner and colleagues (1999) indicated that caring for a family member recognizes the social context as well as the reciprocal relationship that exists between the patient and their family.

The study findings demonstrated strong Buddhist beliefs and values that influence the caregiving experience and expectations. Accordingly, the Thai socio-cultural context, including hierarchy relationships, female gender roles, and changing family structure were found in this study to influence the caregiving experiences. Family caregivers responded to these socio-cultural influences in each stage of the Thriving in Family Caregiving process.

Social relationships in the Thai society are also predominately vertical and hierarchical. The hierarchy is determined by age, wealth, power, knowledge, occupation, and rank. Thus, the family is the place where children learn, at a very young age, to show appropriate respect towards their parents, siblings, relatives, teachers, monks, and others. Children readily learn to accept their social place in the hierarchy. In addition, traditional gender role was assigned woman to take resposbility for nurturing other family menbers as well as care for the sick person. As a consequence, the caregiving role was mandated by this hierarchical relation and traditional gender role. Most participants were female and the youngest child of the family. Hence, they were inescapable to take this caregiving role.

In the Thai culture, gratitude varies from feelings of thankfulness to feelings of obligation to do something in return. Some parents expect only the feeling of appreciation from their children and do not ask for anything in return. These families frequently do not create pressures or guilt feelings in their children. Contrasting families believe children owe something to their parents. This is called the feeling of obligation (Wongsith, 1994). A feeling of gratitude was also another Thai value that tied some of participants with the caregiving role. The participants morally felt obligted to repay goodness to their parent. If a child cannot reciprocate, the child may feel guilt or a sense of failure. As a consequence, some participants used this Thai value to make meaning in care.

In addition, Buddhist beliefs and values prescribed to the model of thriving in family caregiving. Buddhist values described by family caregivers in this study were the law of Karma, the concepts of *Bun* (merit) and *Bab* (demerit), past life and rebirth, and dharma (Payutto, 1997). The law of Karma depicts that good acts will lead to good consequences and bad acts will lead to bad results. Making of boon (merit or good karma) and avoiding making of Bab (demerit or bad karma) are directly related to certain outcomes. Rebirth is the result of one's own Karma. Meritorious Karma leads to a good rebirth and de-meritorious Karma leads to a bad one (Payutto, 1997; Reinhard, 2017). Providing care for ill or sick family members dependent on HMV is valued as a good person and merit-making while neglecting to do this role is a bad person and 'Bab'(sin) occurs. They will face on-going adverse situations and events in their lives. This religious belief on the law of karma influenced the participants to make sense of their caregivng experiences. It helps them feel control.

Although the Buddhist value of gratefulness is firmly rooted in the Thai culture (Podhisita, 2012), changing the social structure and the decreasing family size will result in fewer family members. This, in turn, could result in the lack of family members to provide care. Therefore, it is inevitable that a certain percentage of chronic critically-ill people will have limited or no family assistance. In the face of modernization, understanding the traditional family care approach to HMV will be an on-going challenge when designing an effective home care system in Thailand. This reflects recent government efforts to shift decision-making from the centralized, public health service system to local agencies and the need for more local community assistance for technology dependent Thais at home.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

The goals of this final chapter are to highlight the study contributions and various recommendations for nursing practice and education, future research, improvements in healthcare policy, and present the study's strengths and challenges.

Conclusions

The purpose of this study is to generate a substantive model to describe the successful process of Thai family caregiving for patients with home mechanical ventilation (HMV). This study specifically explored how Thai family caregivers of HMV patients perceived caregiving situations, how they coped and adjusted to their caregiving role, and how they dealt with the consequences they faced in the caregiving process. The study addressed participant characteristics and the main categories and sub-categories generated from the Straussian grounded theory analysis.

The study participants were 16 families with 22 individuals who were mostly female and the primary caregivers. They were all Buddhist. Most were adult married caregivers with no underlying diseases. The majority of the participants lived in rural areas of Songkhla province with low educational levels and low-income jobs. Household income derived from their own work and/or provided by other family members. Most of the participants were children of the patient. The majority of the caregiving with HMV patient varied from short-term to long-term caregiving experience.

In terms of dependent HMV patients, the majority was elderly (over 65 years old). The most commonly reported cause of prolonged ventilator use was acute respiratory failure along with other chronic conditions such as Alzheimer's, stroke, femur fractures, breast cancer, and heart failure). All the patients were Buddhist and had total 24-hour nursing care delivered by the family. The level of consciousness ranged from alert and orientated to unresponsiveness. Regarding healthcare coverage, most patients were covered by the government's Universal Coverage Scheme (UCS).

The theoretical model explanation the transformation of perception and managing as family caregivers were moving along in the process of experiencing them provide care was called "the model of thriving in family caregiving." This explanatory model emerged from the perspectives of the family caregivers that emerged from their everyday lived experiences. The model of *Thriving in Family Caregiving* in this study was the successful family caregiving process for their loved one dependent on HMV. It consisted of three major processes: being in the midst of a storm and a labyrinth of suffering, doing one's best to move on, and achieving blissfulness of mind. The process described transforming participants' perspectives and adjusting their management styles to provide care for home ventilated patients. The transformation encapsulated from being in the midst of a storm and a labyrinth of suffering to achieving thriving in care. to greater flexibility and balance in their life.

Becoming to care for family member with HMV, the caregiver perceived their experience of caregiving as *being in the midst of a storm and a labyrinth of suffering.* In this stage, the family caregiver confronted with feelings of incompetence, competing demands of multiple roles, being overwhelmed, and quest for the meaning of care. Many questions are running in their mind all the time as why they have to be a caregiver and what is the meaning of care however the answers have still not found.

Despite the family caregivers are remaining feeling of being in the midst of a storm and a labyrinth of suffering, enrolling to caregiver role as they felt inescapability. The participants told themselves have to move on through caregiving life because neglecting care for vulnerable family member who dependent on HMV meant allowing them face with dying. Other people in community might be blamed they as a bad person. The participants have to *move on*, reconstructed their views to accept their caregiving role by making up one's own mind and meaning-making in care. They felt valued and well-adjusted to sustain caregiving. Though adjustments, the participants looked for a way to move forward from a perceived hopeless and suffering situation. They learned to provide complex care, to adjust family life, and to seek support from community and healthcare institute resources. Consequently, the feeling of being in charge of care emerged. The participants felt they could provide care for their patient with HMV either through sustaining life or achieving peaceful death.

Some participants got stuck in this stage viewing family member care as an unavoidable duty with their best effort already put forward. Thai culture influenced how participants provided care and a bad person image equated to neglect. However, some caregivers who were not able to accept and manage the caregiving role found themselves still being in the midst of a storm and a labyrinth of suffering. This, in turn, affected the quality of care and the well-being of both patient and caregiver.

Moreover, some family caregivers who were able to get through the midst of a storm and a labyrinth of suffering gained a fresh new way of thinking – a paradigm shift of finding a new view of bliss in the delivery of care. It was not only surviving or improving incrementally the patient's outcome, but a strong sense of self- fulfillment and deep satisfaction was achieved. The participants felt in complete control of care, a deep sense of pride, a more humanized way of delivering care, and living a balanced life. Thriving in family care was discovered by the caregiver giving care for their loved one with HMV to achieve harmony in life. Following the caregiving process helped in their acceptance of death, a rising happiness level, a transformed perspective, and then finally, a sense of bliss.

Recommendations

Family caregiving for patients with HMV faces great challenges and complex interactive processes involving both patient and caregiver as well as healthcare providers. This study revealed caregiving strategies from moving forward in the caregiving process until achieving thriving in care. The findings also indicated support needs and gaps in care for the home ventilated patient and their caregivers resulting in recommendations for nursing practice, nursing education, further research, and health policy.

Nursing Practice

There are several recommendations for the practice of family caregiving. The model of achieving thriving in family caregiving for a patient with HMV is a very relevant tool for healthcare providers' particular nurses to utilize. Many family caregivers seek strategies for patient care management. Nurses should be familiar with this model. Knowledge of this model could guide nurses to make more informed clinical decisions within their nursing plans. Findings from this study suggest specific family caregiving strategies could help care for home ventilated patients at each stage of the caregiving process.

The initial stage of the family caregiving role of a patient with HMV is being in the midst of a storm and a labyrinth of suffering. Nurses need to *help the family caregiver to accept the role of care*, make specific and respectful wishes of their ventilated patient, encourage positive behaviors, set consistent and clear limits, and work to regulate their own emotions in reducing their own suffering. Family care planning should initially occur in the hospital where family caregivers learn to deliver care and improve their confidence with HMV care. Must decide who will function of family caregivers in term of primary, secondary, and support. For instance, who will provide direct care, negotiate financial arrangements and formal assistance. In addition, regular and frequent visits at home together with phone calling consultancy are needed in the first three months upon hospital discharge. The study indicated that support from healthcare and on-site service care providers helped reduce family caregiver’s suffering when life-threatening situations arose.

Moreover, *facilitating self-help-group support* was deemed important. Nurses could help the caregivers by being the facilitator for caregiving support groups. From the study, it was discovered that caregivers need someone to share their feelings and caregiving experience with. Up until this study, there has not been a support group of family caregivers for patients with HMV in the Hat Yai hospital service area. A support group would allow caregivers to meet other similar individuals. Nurses could facilitate and coordinate meeting locations and set agendas such as the local health center or via on-line social networks.

The second stage, doing one's best to move on, healthcare providers could provide direction and guidance for the family caregivers and their patient. Nursing support to improve caregiver's self-confidence and find the meaning in care of the caregiver were indicated as important. In addition, family caregivers emphasized that a solid nursing relationship is important to move forward in the caregiving process. They moved on into explain how receiving support and encouragement from the nurses were critical. At that time, participants placed value on a nurse's clinical and demonstrated knowledge about caring procedures, open communication, and problem-solving skills. All were seen as improving patient clinical outcomes. These accounts indicate that nurses might best serve family caregivers by being highly collaborative and respectful while providing practical useful care. Family caregivers wanted nurses that were willing to work with them and did not only want to be told how to give care.

Combining the role of an expert with a commitment to collaboration, healthcare providers may best assistance family caregivers and their patient embrace new caregiving strategies and achieve success they are seeking. Nurses could play a significant role in helping find resources and solutions for families that face difficulties with information gathering, social and economic challenges such as insufficient financial means, lacking support systems, or how to access resources. These factors appear to directly influence achieving blissfulness of mind. Nurses can refer cases to social workers or the Sub-District Administration Organization. In the future, the development of home care websites of caregiving resources and consultation benefit and support families who live far away from hospitals. Furthermore, encourage reserve caregiver roles for other family members who do not live with the patient. Other family members could learn basic medical procedures, give emotional support, contribute financial resources, and provide logistical services.

The last stage, achieving blissfulness of mind, nurses should encourage family caregivers to achieve peace of mind via the caregiving role. Nurses should reinforce the critical importance of working in harmony with the life contexts of families. In addition, nurses may want to help encourage caregivers to have a sense of pride, being in touch with humanized care, and maintain balance between the role of caregiver and family responsibilities. This can make caregivers feel good about themselves and achieve the goal of thriving in care.

Nursing Education

Today, there is a growing trend of utilizing medical technology away from the hospital. To enhance nursing students' interests and abilities for working with patients dependent on hi-tech home care in rural communities, rural health-care content and high-tech care need to be included in the curriculum. Nursing educators' teachings should focus on the difficulties and strategies of family members who provide care for their dependent patient at home. This teaching should include the nurses' role in assessing difficulties, family readiness and in promoting family self-confidence to provide care for their loved one. It should also include socio-cultural, financial, and service issues impacting Thai family caregiving. Moreover, the findings also indicate complex caregiving encompassing both attitude and caring procedures. It is a transformation from formal care provided by nurses to informal care provided by family caregivers. Therefore, developing a family care program within a nursing curriculum is needed. Study findings can be utilized to build and support such a family care program.

Further Research

The finding of this study suggest several ways for further research. Firstly, qualitative research would be valuable to describe unsuccessful family caregiving provide care to capture how perceptions and management lead to poor outcomes in term of sudden death of the patient or re-admittance to the hospital. Other qualitative research aims to explore family caregiver's experience and attitude toward providing care for their HMV patient. Perhaps exploration of the meaning of family care for other kinds of technology dependent cases such as peritoneal dialysis and ostomy care. Particularly, in rural communities where resources and assistance are scarce, successful experiences could be shared on how some families found meaning in care, or thriving as family caregivers. Understanding in the above-mentioned areas could help improve care for caregiving families with a technology dependent patient at home.

Likewise, mixed methods approach where the caregiver participates in assessments and interviews during and after care that might promote an effective care model. For instance, research has established that exposure to caregiving intervention leads to changes in family caring attitude and strategies. This, in turn, brings about improved positive outcomes both patients and family caregivers. In addition, this study promotes research and development (R&D) with nursing home technology intervention at each stage of the model. Could this model be applied to larger community settings? For instance, the family caregiving role could shift the highlighting of the intervention more towards focusing on positive directions, emotional regulation, and skills encouragement. This could integrate more troubleshooting and practice opportunities that helps the caregiver apply the intervention more effectively to the context of their life. This study development could add a supporter meeting section as a follow-up to the intervention. It would also be interesting to investigate if the interventional factors identified as important by family caregivers in the study, such as learning about emotional regulation, giving good directions, and participating in role-playing do, in fact, emerge as care process interventions when using quantitative methods.

Health Policy

Findings from this study could help re-shape relevant health policies in accessibility and financial areas for a technology dependent patient and their family at home. Thai national health policy and program responses considered suitable are subject to ongoing adjustment and debate. The highlight issues of policy for discussion may comprise:

First, identification of appropriated resources of funding and practical support for the delivery care services. The three government-funded health schemes - the Civil Servant Medical Benefit Scheme (CSMB), the Universal Coverage Scheme (UCS), and the Social Security Scheme (SSS) need to plan and coordinate their efforts regarding costs, accessibility, and effectiveness so all Thai patients and their families can share in equitable ways. Since most of these financing sources come from the government's budget, one needs to work with government officials on program sustainability issues. The high-tech care systems of the three government funded health schemes need to develop databases on expenditures, service, and quality. These would need to be analyzed and integrated effectively into the health care system for all Thais. Moreover, ensuring equality of access and provision of care services for all ages, home area, and financial based on need were required as importance.

Second, one needs to consider the coordination and integration of social and health insurance services in order to afford a continuum of care. Thai health insurance does a poor job of covering home care technology. Health policies in Thailand have not lead to the creation of a health insurance that covers medical technology devices. A pressing issue for policy-makers should be how to support family caregivers in adapting to financial health-related issues in a system dominated by market characteristics. One solution might be the creation of an insurance mechanism where the family caregiver is paid. This kind of insurance would guarantee that services continue to be provided, even if money changes hands. Contributions to health insurance funds on behalf of the non-working populations in most countries should be made through transfers from other social insurance funds such as pension funds, unemployment, or from various government budgets. Health insurance funds have often provided healthcare services to the whole population despite the lack of influential income. The result has been large monetary deficits in the health insurance funds. The further delineation of the extent of the problem and innovative strategies to address it constitute important advances for public healthcare systems as they try to serve their communities. The study findings indicate family caregivers would use this type of funding under a service purchase agreement including a reimbursement mechanism.

Lastly, to encourage community participation in providing care for ventilated patients at home, health care providers promote continuity of care. Healthcare providers can use strategies, planning, and collaboration to improve the provision of long-term care facilities to serve the needs of ventilator dependent patients and their families. For example, gain support from Sub-District Administration Organization in providing medical supplies and instruments: ventilators, mobile suctioning units, oxygen concentrators, sterile water, and wound care supplies. In addition, support for various medical machines and maintenance to ensure that patients receive a higher standard care of treatment at affordable costs.

Strengths and Challenges

This was the first study to employ the grounded theory of research design in family caregiving experience for patients with HMV in Thailand. The findings of this study, therefore, are highly relevant. For example, the data suggests a caregiving process that was influenced by multiple life contexts. The theory developed in this study ability to provide new insights that can inspire continued research and a further understanding into the family caregiving process.

The findings of this study are unique to the Thai culture and the value it places on family caregiving for home ventilated patients. Because family caregiving is such an embedded, long-term cultural assumption, Thai people may have taken the concept of family caregiving for granted. Making the cultural value of family caregiving explicit as an aspect of conceptual modeling is crucial for a better understanding of family caregiving in the Thai culture. This perspective may add an in-depth understanding and specific distinctions of caregiving in the Thai culture, yet at the same time, Thailand is experiencing rapid changes in population, family structure, economy, and family social values.

Spiritual and socio-cultural values of meaning in family caregiving are the core of maintaining Thai caregiving for a ventilator dependent patient at home. Cultural contextual issues of hierarchical relationships between family kin, social obligations, and religious beliefs are deeply grounded in the Thai culture. These cultural contextual factors play important roles in guiding a Thai family caregiver in taking care of a family member. Moreover, it was found in this study that family caregivers still value meaning in life as an important spiritual and social cultural value.

However, study findings should be reflected in light of few limitations. As a qualitative research, the findings revealed here are not proposed to be generalized. It is expected that other scholars might use the study findings after accepting the context unique attaching of this research. Especially, the family caregiving theory developed in this study was based on the experiences reported primary and secondary family caregivers living in a restricted geographical area of Songkhla province. The study sample consisted of only Thai family caregivers; thus, this lack of ethnic/racial diversity is important to consider when interpreting and applying the findings. In addition, only successful caregivers in providing care were eligible for this study. Confirmation of study findings using theoretical sampling frames and additional research methods would have considerably strengthened the transferability of the study results.

Summary

This study has a number of recommendations for change. A review of previous studies of family caregiving process for HMV patients in Thailand has never been conducted or reported. Providing care for these patients face great challenges and complex interactive processes involving both patients and family caregivers as well as healthcare providers. There is a need to explore perceptions and adaptive responses to the experiences of Thai family caregivers of a ventilated patient at home. This study provides a greater understanding of the participants' perspectives of their giving care and the process of moving forward. It has provided a deeper understanding of the psycho- socio and cultural contexts of care management. This knowledge can subsequently be utilized by healthcare providers to implement culturally sensitive care for Thai families with a HMV patient. Moreover, national health care policies need to be developed based on research findings to encourage health caregivers to establish better HMV discharge planning and better family support for sustaining technology care at home. Specified the important contributions families make to home health care in Thailand, investigators, rural clinicians, and policy makers need to better recognize and accept family home care as a real family contribution and cultivate more effective ways to support families and other family members as the primary caregivers in rural communities.

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APPENDIXS

APPENDIX A

Interview Guide

Interview questions to collect data were generated by the research, dependent on the researcher question that can be flexible and adapt to the context of the conversation between researcher and participant. After that, the research questions to justify a specific depth for complex situation of collecting data. For questions on the data collected are as follows.

1. Process or strategy of becoming to caregiver and how to move forward?

1.1 How do you feel? when you need to be caregiver for patient with HMV

1.2 What is the reasons? And what is factor influencing to be caregiver?

1.3 How does the patient in each moment? How is changing?

1.4 How about the knowledge, understanding, managing and feeling of caregiver in each moment? And How is changing?

1.5 How does caregiver do to generate caregiver role? What has been changed? And what is going to do in the further?

1.6 What are the barriers at each stage of caregiving? And how you do to overcome?

1.7 How does effect of caregiving patient dependent ventilator at home?

1.8 How can caregiver do to successful and continuing care for patient with HMV?

1.9 Have you ever been hopeless or powerlessness? How do you do to recovery?

1.10 How is your goal to care patient with HMV?

2. What is the condition that effect to changing of caregiver?

2.1 What is characteristic of caregiver ideal for patient with HMV?

2.2 What is the reason to do caregiver role until now?

2.3 How is decision or inspiration to do caregiver role?

2.4 What is the reason to change yourself or strategy of caregiving during do caregiver role?

2.5 Who/ what is situation can effort to provide successful care for patient with HMV?

2.6 How can you develop caregiver role to provide for patient with HMV?

3**. What is consequent of caregiving?**

3.1 How are affecting of strategy of care, knowledge, and perception of caregiving that change in each moment to caregiver and family?

3.3 What is the outcome after caregiver do to manage care for patient with HMV?

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Interview Guide (Thai Version)

(แนวคำถามในการสัมภาษณ์)

แนวคำถามในการเก็บข้อมูลสร้างขึ้นตามวัตถุประสงค์การวิจัย ซึ่งจะเป็นเพียงแนวทางที่สามารถยืดหยุ่นและปรับไปตามบริบทของกระบวนการสนทนา ปฏิสัมพันธ์ของผู้วิจัยกับผู้ให้ข้อมูล การวิจัยในแต่ละสถานการณ์ หลังจากนั้น ผู้วิจัยจะปรับคำถามให้มีความลึกซึ้งเฉพาะเจาะจงตามความซับซ้อนของการสะสมข้อมูลจากการวิเคราะห์ สำหรับประเด็นคำถามในการเก็บข้อมูล มีดังนี้

1. กระบวนการหรือวิธีการผู้ดูแลเป็นอย่างไร ดำเนินไปอย่างไร

1.1 เมื่อต้องมาเป็นผู้ดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้าน ญาติรู้สึกอย่างไร

1.2 เพราะอะไรจึงต้องมาเป็นผู้ดูแลผู้ป่วย และปัจจัยอะไรบ้างที่ส่งผลให้ต้องมาเป็นผู้ดูแลผู้ป่วย

1.3 กิจกรรมการดูแลผู้ป่วยในแต่ละช่วงเวลาเป็นอย่างไร เปลี่ยนแปลงไปอย่างไร

1.4 ความรู้ ความเข้าใจ วิธีการดูแล และความรู้สึกของญาติในแต่ละช่วงเวลาเป็นอย่างไร และเปลี่ยนแปลงไปอย่างไร

1.5 การที่ต้องมาเป็นผู้ดูแลผู้ป่วยที่บ้าน ญาติต้องเปลี่ยนแปลงตนเองอย่างไรบ้าง อะไรที่เปลี่ยนแปลงไปแล้ว และอะไรที่กำลังต้องปรับปรุงเรียนรู้เพิ่มต่อไป

1.6 ปัญหาและอุปสรรคในแต่ละช่วงของการเป็นผู้ดูแลเป็นอย่างไร และญาติได้แก้ปัญหาต่างๆ อย่างไร

1.7 ผลกระทบที่เกิดขึ้นเมื่อต้องมาเป็นผู้ดูแลผู้ป่วยเครื่องช่วยหายใจที่บ้านเป็นอย่างไรบ้าง

1.8 ทำอย่างไรญาติจึงสามารถดูแลผู้ป่วยมาได้อย่างต่อเนื่อง และประสบความสำเร็จ

1.9 ญาติเคยท้อแท้ หรือหมดกำลังใจในการเป็นผู้ดูแลหรือไม่ หากเคย สาเหตุคืออะไรและกลับมามุ่งมั่นเช่นเดิมได้อย่างไร

1.10 ญาติมีเป้าหมายในการดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้านอย่างไร

2. โครงสร้างหรือเงื่อนไขที่ส่งผลต่อการเปลี่ยนแปลงของญาติเป็นอย่างไร

2.1 ลักษณะของผู้ดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้านที่ดี ควรเป็นอย่างไร

2.2 เพราะอะไรญาติจึงตัดสินใจเข้าสู่การเป็นผู้ดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้าน หรือเพราะอะไรญาติจึงมาเป็นผู้ดูแล และเพราะอะไรญาติจึงมุ่งมั่นที่จะเป็นผู้ดูแลผู้ป่วยจนทุกถึงทุกวันนี้

2.3 การตัดสินใจหรือแรงบันดาลใจ และความมุ่งมั่นในการเป็นผู้ดูแลเกิดขึ้นเมื่อใด อย่างไร

2.4 เพราะอะไรญาติจึงมีการปรับเปลี่ยนตนเอง วิธีการดูแล ตลอดระยะเวลาการของการเป็นผู้ดูแล

2.5 อะไร/ ใคร/ เหตุการณ์อะไรที่ทำให้ญาติพัฒนาการดูแลผู้ป่วยใช้เครื่องช่วยหายใจได้

2.6 การพัฒนาการเป็นผู้ดูแลของญาติมีวิธีการอย่างไรบ้าง เกิดขึ้นที่ใด เวลาใด กับใครบ้าง

3**. ผลที่เกิดตามมาจากการเปลี่ยนแปลง/การปรับตัวของผู้ดูแล**

3.1 วิธีการดูแลผู้ป่วย ความรู้ ความเข้าใจ และความรู้สึกของญาติที่เปลี่ยนแปลงไปในแต่ละช่วงเวลา ส่งผลต่อชีวิตส่วนตัวของตนเอง การทำงาน หรือครอบครัวหรือไม่ อย่างไร

3.2 ผลที่เกิดขึ้นหลังจากการเปลี่ยนแปลงวิธีการต่างๆในการเป็นผู้ดูแล ผู้ป่วยใช้เครื่องช่วยหายใจที่บ้านเป็นอย่างไรบ้าง

3.3 สิ่งที่ได้จากการเป็นผู้ดูแลเป็นอย่างไร

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APPENDIX B

Recording Form of Research

(แบบบันทึกที่ใช้ในการวิจัย)

Research Title: Thriving in Family Caregiving: A Grounded Theory Study of Thai Family Caregivers of Patients with Home Mechanical Ventilation (HMV)

1. Transcription note

รหัสผู้ให้ข้อมูล……………………..……….เก็บข้อมูลครั้งที่…………………………………….
วันที่…………………..เวลา………..น. วิธีการ………..…………………………………..
บันทึกการถอดเทปครั้งนี้ ตั้งแต่หน้า....................ถึงหน้า.......................รวมทั้งสิ้น.....................หน้า
ตั้งแต่บรรทัดที่...........ถึงบรรทัดที่..............รวมทั้งสิ้น.............บรรทัด
ลักษณะสัมพันธภาพ…………………………………………………………………………..
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…………………………………………………………………………………………...
บริบทของสถานที่และสถานการณ์การเก็บข้อมูล………………………………………………
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ข้อสังเกตอื่นๆ………………………………………………………………………........
…………………………………………………………………………………………...

บรรทัดที่	ข้อความ	coding

2. Theoretical note ครั้งที่…….. วันที่……..

ความคิดเห็น-ข้อสังเกตที่เกิดขึ้น

1…………………………………………………………………………………………….

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3. Field note ครั้งที่……. วันที่…….

การเก็บข้อมูลครั้งต่อไป

1.สิ่งที่ต้องการค้นหาเพิ่ม……………………………………………………………………...

คุณลักษณะของผู้ให้ข้อมูล……………………………………………...........................

ด้วยวิธีการเก็บข้อมูลแบบ…………………………………………………….............

2.สิ่งที่ต้องการค้นหาเพิ่ม……………………………………………………………………...

คุณลักษณะของผู้ให้ข้อมูล……………………………………………………….......

ด้วยวิธีการเก็บข้อมูลแบบ………………………………………………………….......

4. อื่นๆ…………………………………………………………………………….........

4. Open code not ครั้งที่……. วันที่…….

Concept	คุณลักษณะ/ข้อบ่งชี้	Line number

5. Axial node ครั้งที่….. วันที่…………..

เงื่อนไขนำ	ปรากฏการณ์
……………………………………………....	…………………………………………………
……………………………………………	…………………………………………………
……………………………………………	…………………………………………………
……………………………………………	…………………………………………………

บริบทที่ทำให้ปรากฏการณ์คงอยู่

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การกระทำ/การจัดการเพื่อตอบสนองต่อปรากฏการณ์

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เงื่อนไขการกระทำ/การจัดการ

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ผลลัพธ์การกระทำ/การจัดการ

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6. Validating note

ของ การนำเสนอปรากฏการณ์ "กระบวนการการดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้านของญาติ"

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1. การนำเสนอข้อมูลนี้ตรงกับประสบการณ์กระบวนการดูแลผู้ป่วยใช้เครื่องช่วยหายใจของญาติหรือไม่อย่างไร

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2. การนำเสนอข้อมูลนี้มีรายละเอียดเกี่ยวกับคุณลักษณะ เงื่อนไขชีวิตของญาติที่เกี่ยวข้องกับกระบวนการดูแลผู้ป่วยใช้เครื่องช่วยหายใจหรือไม่ อย่างไร

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3. มีประเด็นที่ขาดหายไปหรือไม่ อะไรบ้าง

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4. ข้อมูลนี้เสนอปรากฏการณ์ "กระบวนการดูแลผู้ป่วยใช้เครื่องช่วยหายใจของญาติ" ได้ถูกต้องหรือไม่เพราะเหตุใด

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5. ความคิดเห็นและข้อเสนอแนะอื่นๆ

……………………………………………………………………………………………...

APPENDIX C

Informed Consent Form for the Participant

Research Topic: Thriving in Family Caregiving: A Grounded Theory Study of Thai Family Caregivers of Patients with Home Mechanical Ventilation (HMV)

My name is Monthira Udchumpisai. I am a student in Doctor of Philosophy in Nursing Program, Faculty of Nursing, Prince of Songkla University. I am conducting a research project entitled “successful caregiving process for patient with home mechanical ventilation (HMV): a grounded theory study”. You are an eligible participant who have experiences of caregiving. This study will be done in order to complete my dissertation. The results will be used to approach the patient and family caregiver in order to assess their needs, educate them, and offer individualized care with better understanding.

Your involvement in the study will be strict to a confidential interview. The interview will spend time approximately 45-60 minutes. This may be conducted for about two-three times. If you feel discomfort, evidenced by your verbal expression of non-verbal gestures (crying, etc.) the researcher will be stop the interview and comfort you until you feel better and allow the researcher to continue.

All data will be analyzed by keeping anonymity and used in only academic reports. You can at any time to discontinue your participation in this study. All the interview data from the audio recording will be destroyed after the research project is complete.

For Participant

I understand that I am invited to share my experience on caregiving process of patient with home mechanical ventilation. I understand that this study is being done to fulfil partial requirements for a doctoral degree in nursing program.

I understand all the data collection procedures and all identifying information will be kept separate from research materials. My privacy will be secured by the used of code numbers. I understand that all interviews will be removed prior to the preparation of audio transcriptions. The audio will be kept secure by the investigator and will be destroyed after the research project is complete. I understand that participation in this study is entirely voluntary. I may refuse to participate and can withdraw my consent at any time during the study

Signature …………………………………	Signature …………………….........
Name (…………………………………...)	(Miss Monthira Udchumisai)
(Participant) Date…/…/…	**(Researcher)**
Date…/…/…	

Signature …………………………………	Signature …………………………
Name (…………………………………...)	Name (…………………………….)
(Witness 1) Date…/…/…	**(Witness 2)** Date…/…/….

เอกสารขอความยินยอมก่อนการเข้าร่วมการวิจัย

ข้อมูลเกี่ยวกับงานวิจัย

ดิฉันนางสาวมลธิรา อุดชุมพิสัย เป็นนักศึกษาปริญญาเอก สาขาการพยาบาล คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ กำลังดำเนินการวิจัย*เรื่อง “กระบวนการสู่ความสำเร็จการดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้าน: วิธีการวิจัยแบบสร้างทฤษฎีจากข้อมูล”*งานวิจัยนี้มีวัตถุประสงค์เพื่อจะทราบว่า ญาติผู้ดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้าน มีกระบวนการดูแลผู้ป่วยอย่างไร และมีโครงสร้างของเงื่อนไขอะไรบ้างที่เกี่ยวข้องกับการปรับเปลี่ยนแต่ละช่วงเวลาของการเป็นผู้ดูแล

การวิจัยครั้งนี้ ผู้วิจัยได้กำหนดว่าจะเก็บข้อมูลจากญาติผู้ดูแลผู้ป่วยใช้เครื่องช่วยหายใจจนประสบความสำเร็จ คือ สามารถดูแลผู้ป่วยได้อย่างต่อเนื่องเป็นเวลามากกว่า 3 เดือน ท่านเป็นผู้หนึ่งที่ได้รับการคัดเลือกโดยวิธีการแนะนำจากพยาบาลผู้ให้การดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้าน ผู้วิจัยใคร่ขอเชิญท่านร่วมเป็นผู้ให้ข้อมูลท่านหนึ่ง ในการเก็บข้อมูล ผู้วิจัยจะสนทนากับท่านโดยใช้เวลาครั้งละประมาณ 2 ชั่วโมง ซึ่งผู้วิจัยจะขอบันทึกเสียงในการสนทนาด้วย และขอเข้าสังเกตการดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้านของท่าน โดยท่านจะเป็นผู้ตัดสินใจให้ผู้วิจัยเข้าร่วมในกิจกรรมต่างๆ หรือไม่ก็ได้ หรือเป็นเพียงบางกิจกรรม หรือเป็นครั้งคราวก็ได้ ตามความสะดวกใจและความสมัครใจของท่าน อย่างไรก็ตามระหว่างที่มีการสนทนาหากพบว่าผู้ป่วยมีอาการเปลี่ยนแปลง หรือต้องการการดูแล การสนทนาระหว่างผู้วิจัยและผู้ให้ข้อมูลจะหยุดลงชั่วคราวเพื่อให้ผู้ให้ข้อมูลได้ให้การดูแลผู้ป่วย และหลังจากนั้นจึงจะเริ่มการสนทนาต่อเมื่อผู้ให้ข้อมูลพร้อม

ข้อมูลหลักในการวิจัยจะเป็นการสนทนากันเรื่องการให้การดูแลผู้ป่วยใช้เครื่องช่วยหาใจที่บ้านว่าเปลี่ยนแปลงไปอย่างไรบ้าง เพราะอะไร ซึ่งข้อมูลจะเกี่ยวกับความรู้ความเข้าใจ ทักษะ ความรู้สึกเกี่ยวกับวิธีการดูแล การปรับเปลี่ยนบทบาท ความมุ่งมั่น ปัญหาอุปสรรค การแก้ไข รวมทั้งอุปนิสัยส่วนตัวและภูมิหลังที่เกี่ยวข้องกับหัวข้อดังกล่าว ข้อมูลที่ได้จากท่านและผู้ดูคนอื่นๆ ผู้วิจัยจะไม่นำไปเปิดเผยแก่บุคคลอื่น เมื่อการศึกษาได้รับการเผยแพร่ จะไม่มีการระบุชื่อ หรือข้อมูลที่เป็นการอ้างถึงตังท่านเอง ข้อมูลจะเป็นภาพรวมของญาติผู้ดูแลผู้ป่วยเท่านั้น และเมื่อจบการดำเนินการวิจัย ข้อมูลทั้งหมดจะถูกทำลาย

ในการให้ความร่วมมือในครั้งนี้ ไม่มีอะไรที่เป็นความเสี่ยงสำหรับตัวท่าน แต่จะเป็นข้อมูลที่เป็นประโยชน์สำหรับพยาบาลในการให้การดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้านรวมทั้งญาติตลอดจนครอบครัวผู้ดูแล ผู้วิจัยหวังว่าผลการวิจัยจะเป็นแนวทางให้กับญาติผู้ดูแลผู้ป่วยใช้เครื่องช่วยหายใจที่บ้านท่านอื่นๆ ในการปรับเปลี่ยนตนเองเพื่อห้ามารถดูแลผู้ป่วยได้อย่างประสบ

ความสำเร็จ และเป็นแนวทางให้กับผู้เกี่ยวข้องนำไปพัฒนาบทบาทของผู้ดูแลได้อย่างเหมาะสมและกว้างขวางขึ้นกว่าที่เป็นอยู่ในปัจจุบันนี้ด้วย

ในการสนทนาหรือการให้ข้อมูลใดๆ ที่เกี่ยวข้องกับเรื่องส่วนตัว และทำให้ท่านรู้สึกไม่ค่อยสะดวกใจที่จะตอบคำถามหรือให้ข้อมูลอื่นใด ท่านมีสิทธิ์ที่จะไม่ให้คำตอบข้อหนึ่งข้อใด หรือการให้ข้อมูลหนึ่งข้อมูลใดก็ได้ แต่ถึงอย่างไร ผู้วิจัยใคร่ขอความร่วมมือท่านในการพยายามให้ข้อมูลตามสิ่งที่เป็นมากที่สุด เพราะคำตอบ ความคิดเห็น หรือข้อมูลต่างๆ ของท่านจะไม่มีถูกหรือผิด เป็นความคิดเห็นส่วนโดยส่วนตัว

การมีส่วนร่วมในการให้ข้อมูลในการวิจัยครั้งนี้ เป็นความสมัครใจของท่าน ท่านมิสิทธิ์จะของดการให้ความร่วมมือเมื่อใดก็ได้ โดยจะไม่มีผลกระทบต่อตัวท่าน หรือผู้ที่เกี่ยวข้องกับตัวท่านแต่อย่างใด

ที่เรียนท่านมาทั้งหมดนี้ หากยังมีสิ่งใดที่ไม่ชัดเจน หรือหากท่านมีข้อสงสัย ได้โปรดถามดิฉันซึ่งเป็นผู้วิจัย จะช่วยอธิบายแก่ท่านจนเป็นที่พอใจ

การให้ความยินยอม

ข้าพเจ้าได้อ่านเอกสารขอความยินยอมนี้ และได้มีโอกาสถามข้อสงสัยจนเป็นที่พอใจแล้ว ข้าพเจ้าได้รับทราบและเข้าใจวัตถุประสงค์ของการวิจัยโดยละเอียด ข้าพเจ้ายินดีให้ความร่วมมือในฐานะผู้ให้ข้อมูล ทั้งนี้ข้าพเจ้าเข้าใจดีว่า ข้าพเจ้ามีสิทธิ์ของดการให้ความร่วมมือได้ทุกเมื่อ ถ้าต้องการ โดยไม่ทำให้เกิดผลกระทบต่อตัวข้าพเจ้าและผู้ป่วยไม่ว่าเรื่องใดและทางใด

ลงชื่อ…………………………………………	ลงชื่อ……………………………………………
(……………..……………..………….)	(นางสาวมลธิรา อุดชุมพิสัย)
(ผู้ให้ข้อมูล) วันที่…………………….	**(ผู้วิจัย)** วันที่……………………………….
ลงชื่อ…………………………………………	ลงชื่อ……………………………………………
(…..………………………………….)	(……………………………………..)
(พยานคนที่ 1) วันที่…………………	**(พยานคนที่ 2)** วันที่…………………

APPENDIX D

Demographic Data of Patient and Family Caregiver

Thesis Title: Thriving in Family Caregiving: A Grounded Theory Study of Thai Family Caregivers of Patients with Home Mechanical Ventilation (HMV)

Explanation: The instrument for collecting demographic data is composed of two parts

Part 1 Demographic data of patient

Part 2. Demographic data of family caregiver

Date......./............/.............

No...............................

Part 1 Demographic data of patient

Explanation: Please mark / into the box ☐ or fill in the gaps

1. Sex

☐ 1. Male ☐ 2. Female

2. Age…………………… years

3. Marital Status

☐ 1. Single ☐ 2. Married ☐ 3. Separated /divorced

4. Education

☐ 1. Unschooled ☐ 2. Primary School

☐ 3. Secondary School ☐ 4. Vocational / Diploma

☐ 5. Bachelor degree ☐ 6. Postgraduate

5. Religion

☐ 1. Buddhism ☐ 2. Islam ☐ 3. Christian ☐ 4.Other………..

6. Career (before illness)

☐ 1. Not employed / retired ☐ 2. General career

☐ 3. Official ☐ 4. Shopman

☐ 5. Agriculturist ……………. ☐ 6. Student

☐ 7. Personal Business ☐ 8. Other…………………..

7. Diagnosis ………………………………………………………………………..

………………………………………………………………………..............

8. Present illness during admission ……………………………..

……………………………………………………………………...............

……………………………………………………………………………...

……………………………………………………………………………...

9. General appearance of patient ……………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

Part 2 Demographic data of family caregiver

<u>Explanation:</u> Please mark / into the box ☐ or fill in the gaps

1. Sex

☐ 1. Male ☐ 2. Female

2. Age…………………… years

3. Marital Status

☐ 1. Single ☐ 2. Married ☐ 3. Separated /divorced

4. Education

☐ 1. Unschooled ☐ 2. Primary School
☐ 3. Secondary School ☐ 4. Vocational / Diploma
☐ 5. Bachelor degree ☐ 6. Postgraduate

5. Religion

☐ 1. Buddhism ☐ 2. Islam ☐ 3. Christian ☐ 4.Other………..

6. Career

☐ 1. Not employed / retired ☐ 2. General career
☐ 3. Official ☐ 4. Shopman
☐ 5. Agriculturist ……………. ☐ 6. Student
☐ 7. Personal Business ☐ 8. Other…………………...

7. Income / month

☐ 1. < 1,000 Bath ☐ 2. 1,001 - 5,000 Bath
☐ 3. 5,001 – 10,000 Bath ☐ 3. 10,001 - 15,000 Bath
☐ 4. 15,001 – 20,000 Bath ☐ 4. > 20,000 Bath

8. Relationship with patient…………………………………………………………………

9. Secondary caregiver ………………………………………………………………………..

…………………………………………………………………………………

10. Duration time of caring patient with HMV………………………...months

APENDIX E

Summary of Participants and Theoretical Sampling

Participant's name	Gender	Age (year)	Caregiver role	Marital status	Education	Physical health status	Relationship to ventilated patient	Duration of caring (months)	Employment status	Household Monthly Income (Bath)	Residential area	Level of patient's dependency	Theoretical sampling
1. Chaba	female	42	primary	married	secondary school	migraine	daughter	30	laundry	15,000	rural	Totally dependent	At the beginning a purposive convenience sample of three family caregivers. Thai ethnicity, able to speak and understand Thai language, living in areas of Songkhla, having experience for take care patient with HMV for at least 3 months
2. Champa	female	53	primary	married	primary school	none	daughter	10	rubber planner	10,000	rural	Totally dependent	
3. Mali	female	42	primary	married	Primary school	none	daughter	60	Un-employ	10,000 (FM support)	rural	Totally dependent	
4. Payom	female	23	primary	single	Bachelor degree	none	daughter	1	Un-employ	10,000 (FM Support)	rural	Totally dependent	- Entering successful weaning off the ventilator or peaceful death less than 3 months - Lifespan of the caregiver
5.Chongko	female	43	secondary	married	Bachelor degree	none	daughter	2	Government official	30,000	sub-urban	Totally dependent	
6. Kalong	female	64	primary	wife	Primary school	DM	wife	2	unemployed	0 (FM Support)			
7. Saiyhud	female	78	primary	Widowed	Primary school	HT	mother	2	unemployed	0 (FM Support)	rural	Totally dependent	
8. Kulab	female	70	primary	Widowed	Bachelor degree	Post SDS	daughter	4	Retried	20,000	sub-urban	Totally dependent	Accepting the caregiving role

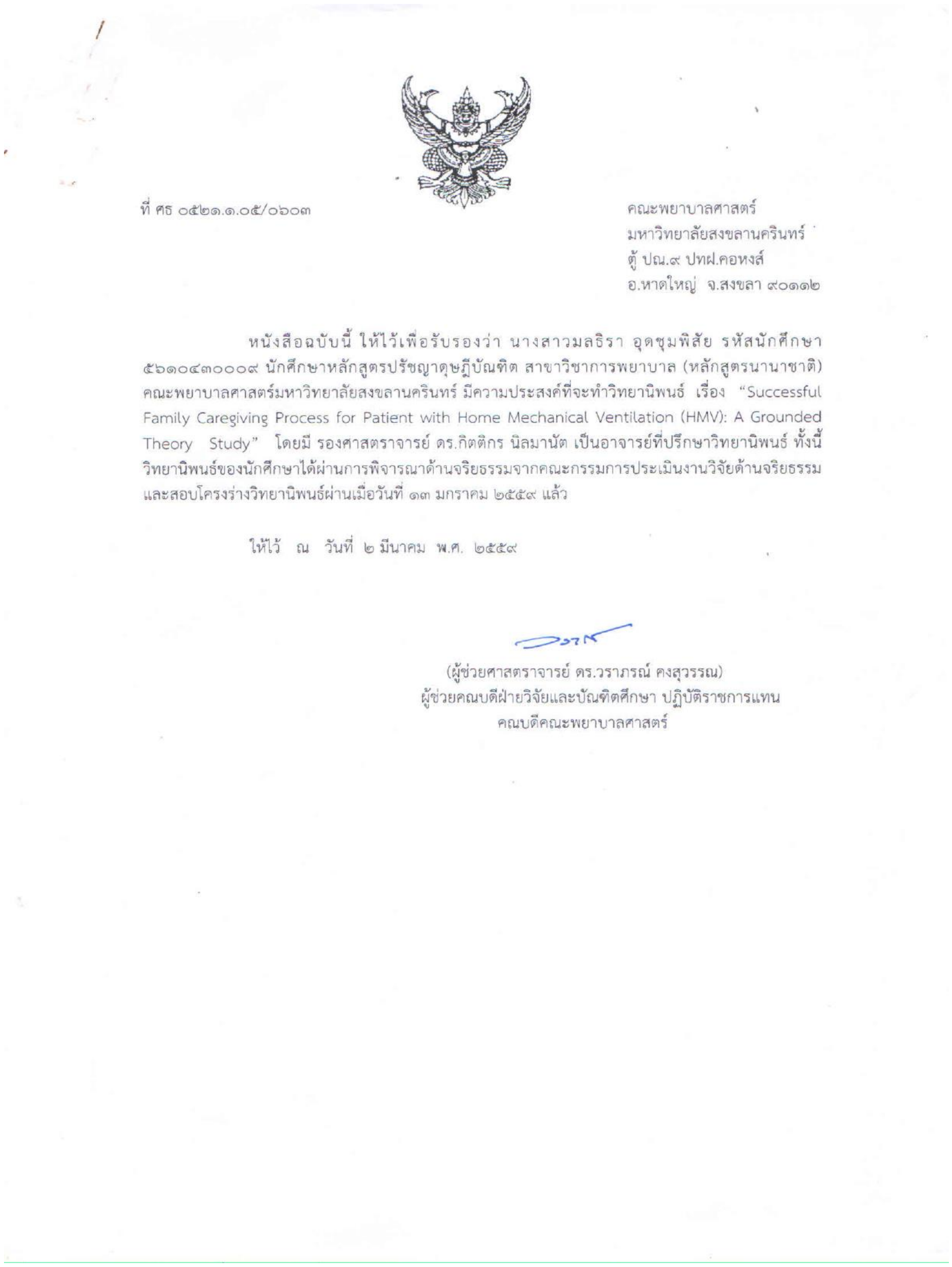
Participant's name	Gender	Age (year)	Caregiver role	Marital status	Education	Physical health status	Relationship to ventilated patient	Duration of caring (months)	Employment status	Household Monthly Income (Bath)	Residential area	Level of patient's dependency	Theoretical sampling
9. Pikul	female	55	primary	widowed	Primary school	HT	daughter	6	Un-employ	15,000 (FM support)	rural	Totally dependent	
10.Pradoo	male	33	Primary	single	Secondary school	Post TBI	older brother	10	Un-employ	5,000 (FM support)	rural	Totally dependent	- Explore one who is not the child but the spouse, parent or sibling of the patient - Education differential of caregiver, primary school to bachelor degree - Explore secondary caregiver
11.Fuengfah	female	28	secondary	married	Bachelor degree	none	wife	10	Food street seller	5,000			
12. Kaew	male	60	secondary	divorce	diploma	none	uncle	2	Rubber planner	15,000	rural	Totally dependent	
13.Banchuen	female	32	primary	divorce	Primary school	none	older sister	3	Un-employ	0	rural	Totally dependent	
14.Sangchan	female	66	secondary	widowed	Primary school	none	mother	3	Rubber planner	5,000			
15. Kajohn	male	45	secondary	marrided	Primary school	none	son-in-law	60	Rubber planner	10,000	rural	Totally dependent	
16. Koon	male	57	primary	married	diploma	none	husband	3	Company official	15,000	sub-urban	Totally dependent	
17. Bunnak	male	55	primary	married	Secondary school	none	son	3	fireworks business owner	1,500	rural	Totally dependent	- Gender of the caregiver, to explore male caregivers - Explore family who hire caregiver
18. Mok	male	44	Primary (hire caregiver)	married	Bachelor degree	none	son	8	Building business owner	40,000	rural	Totally dependent	
19. Unchan	female	59	primary	single	Primary school	none	daughter	5	Food street seller	40,000	sub-urban	Totally dependent	

Participant's name	**Gender**	**Age** (year)	**Caregiver role**	**Marital status**	**Education**	**Physical health status**	**Relationship to ventilated patient**	**Duration of caring (months)**	**Employment status**	**Household Monthly Income (Bath)**	**Residential area**	**Level of patient's dependency**	**Theoretical sampling**
20. Champee	male	57	secondary	Married	Secondary school	migraine	son	8	Rubber planner	10,000	rural	Totally dependent	Explore health care coverage: UCS, CSMBS, SSS, and cash
21. Ratree	male	60	primary	Married	Primary school	none	daughter	4	Rubber planner	15,000	rural	Totally dependent	
22. Lamduan	male	39	primary	Married	Bachelor degree	none	daughter	36	Silver platting business owner	40,000	rural	Totally dependent	

FM = Family members
DM = Diabetes mellitus
HT = Hypertension
post SDS = post spinal discs surgery
post TBI = post traumatic brain injury
UCS = The Universal Coverage Scheme
CSMBS = The Civil Servant Medical Benefit Scheme
SSS = the Social Security Scheme

Appendix F

IRB Approval



ที่ ศธ ๐๕๒๑.๑.๐๕/๐๖๐๓

คณะพยาบาลศาสตร์
มหาวิทยาลัยสงขลานครินทร์
ตู้ ปณ.๙ ปทฝ.คอหงส์
อ.หาดใหญ่ จ.สงขลา ๙๐๑๑๒

หนังสือฉบับนี้ ให้ไว้เพื่อรับรองว่า นางสาวมลธิรา อุดชุมพิสัย รหัสนักศึกษา ๕๖๑๐๔๓๐๐๐๙ นักศึกษาหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (หลักสูตรนานาชาติ) คณะพยาบาลศาสตร์มหาวิทยาลัยสงขลานครินทร์ มีความประสงค์ที่จะทำวิทยานิพนธ์ เรื่อง "Successful Family Caregiving Process for Patient with Home Mechanical Ventilation (HMV): A Grounded Theory Study" โดยมี รองศาสตราจารย์ ดร.กิตติกร นิลมานัต เป็นอาจารย์ที่ปรึกษาวิทยานิพนธ์ ทั้งนี้ วิทยานิพนธ์ของนักศึกษาได้ผ่านการพิจารณาด้านจริยธรรมจากคณะกรรมการประเมินงานวิจัยด้านจริยธรรม และสอบโครงร่างวิทยานิพนธ์ผ่านเมื่อวันที่ ๑๓ มกราคม ๒๕๕๙ แล้ว

ให้ไว้ ณ วันที่ ๒ มีนาคม พ.ศ. ๒๕๕๙

(ผู้ช่วยศาสตราจารย์ ดร.วราภรณ์ คงสุวรรณ)
ผู้ช่วยคณบดีฝ่ายวิจัยและบัณฑิตศึกษา ปฏิบัติราชการแทน
คณบดีคณะพยาบาลศาสตร์

APPENDIX G

Participant and Family Descriptions

Chaba (ชบา)

Chaba is a 42-year-old married daughter of a home ventilated father (patient). Her 44-year-old husband is a private company employee. They also have two school age children. High school educated Chaba is the youngest of 11 children of the patient. Initially, her parents stayed in their own home close to Chaba's home. In the meantime other siblings have gotten married and live in different provinces far from her home. Later on her father got sick forcing her parents to move in with Chaba. Chaba also provides care for her mother who is classified as moderate level for left hemiplegia due to an ischemic stroke. She has taken on the role of a primary caregiver for nearly three years without a secondary caregiver. Her 96-year-old father is blind due to glaucoma. Aspiration pneumonia was the diagnosis for his prolonged ventilator use. He is at the conscious level of pain responsiveness, on nasal gastric (NG) tube feeding, and without pressure ulcers. When she has to leave the home, family members watch the patient for ventilator malfunction. Consequently, she does very little activity outside the home. Her previous job was to do laundry at home. Now she is given money from a brother who cannot provide care for their ventilated father.

Patient Characteristics

Her 96-year-old father is blind due to glaucoma that occurred seven years before he became dependent on HMV. Aspiration pneumonia was the diagnosis for his prolonged ventilator use. He is at the conscious level of pain responsiveness, on nasal gastric (NG) tube feeding, and without pressure ulcers. In addition, he has a tracheostomy tube with home ventilator (ViVo brand) with assist/control mode – the patient is able to initiate assisted breathing. The respiratory rate is established by a set machine rate plus any spontaneous breathing from the patient. The setting was inspiratory positive airway pressure (IPAP) 20 cmH_2O, expiratory positive airway pressure (EPAP) 5 cmH_2O, and a respiratory rate (RR) of 18 breaths per minute. The respiratory parameter was tidal volume (TV) 200-300 ml, RR of 18-23 breaths per minute without signs of dyspnea or cyanosis. Normal lungs sound, low volume of throat secretion, and oxygen saturation of 95% were found.

Home Setting Characteristics

Chaba's home is a two-story townhouse, left margin of all four building. The house is located in Banpru Sub-district, Hat Yai district and nine kilometers from Hat Yai Hospital. On the first floor, the open space includes the patient's bed, various machines (ventilator, oxygen concentrator, and mobile suctioning), the mother's bed, living and dining areas. Equipment and supplies were put on table close to the patient's bed. Two side windows bring in light. On the other side of the open area are a kitchen, a bathroom, and a ladder leading to the 2nd floor.

Champa (จำปา) and Champee (จำปี)

Champa is a 53-year-old married female who is a primary caregiver for her HMV dependent mother of 10 months. She has a primary level education. She and her husband are farmers with two adult children. One daughter works in their sub-district government office while the other one is in college. Champa is the 3rd of four children. The Champa's and mother's houses are adjacent to each other. The oldest sister's house is located nearby, but a serious illness precludes her from a caregiving role. The youngest sibling is a married brother who works in another province and cannot provide care. However, he does send money to buy medical supplies and other stuff. Champa has voiced frustration that she has to earn income and also care for her mother. *Champa*'s mother was 78-year-old female who was diagnosed with breast and lung cancer along with brain metastasis. She has declined chemo-therapy and preferred her last moment of life to be at home. Her alert level is consciousness and is oriented. She must stay on the ventilator because of her lung condition. She needed suction several times a day.

Champee is a male 57-year-old married, 2nd of children of the patient and fulfills the role of secondary caregiver. He also has a secondary level 6th grade education but lives in another district, Sadoaw. Champee can provide care procedures for the mother both respiratory care with the machine and maintaining daily living. Champa is very comfortable having Champee as the second caregiver.

Patient Characteristics

Patient is 78-year-old female who is diagnosed with breast and lung cancer along with brain metastasis. She has declined chemo-therapy and prefers her last moment of life to be at home. Her alert level is consciousness and is oriented. She must stay on the ventilator because of her lung condition. The patient has a tracheostomy tube with a ventilator (ViVo brand) – the control mode of the ventilator delivers controlled only breathing to the patient. The ventilator is triggered by a pre-set rate, and inspiration is geared to pre-set cycle variables. She has no signs of dyspnea or cyanosis while she has shown a tidal volume (TV) of 200-350 ml., a respiratory rate of 16-26 breaths per minute, IPAP 16 cmH_2O, and EPAP 5 cmH_2O. A high volume of throat secretion was found and she needed suction several times a day. The patient has a distorted voice/sound that might be caused by hyper granulation tissue around the tracheostomy. She refuses to return to the hospital and rejects any other forms of treatment.

Home Setting Characteristics

The patient's home is located in Klong Pea sub-district, Na Mhom district and 25 km from Hat Yai Hospital. The one-story home is in the old traditional Thai style. It has trees and a feeling of openness remain around the house. Inside the house, the patient lives in an open floor plan with her bed, ventilator, mobile suctioning, and oxygen concentrator. Also included in the same living area are: the caregiver's bed, a refrigerator, shelves, and a dresser. This location the patient to hear or listen to other family members. The right side of the living space has two windows bringing in ventilation and light.

Mali (มะลิ) and Kajohn (ขจร)

Mali is the 42-year-old married daughter of the ventilated patient. She has a primary level education and works as a rubber tapper. *Forty-five-year-old Kajohn* is Mali's husband and was designated as the secondary caregiver. They have two college children.

Mali as the youngest child of 11 children has taken the role of primary caregiver for her mother five years. She also inherits the family roles of wife, mother, and housekeeper. Other siblings are married and reside in other provinces. After the mother came home on the ventilator, Mali was the only available caregiver. Mali's older sister lives in Pattani province and is unable to provide care. She, though, sometime helped with housework. The patient's cost of care was her own savings; however, other costs such as transportation, food, and utilities were paid by Mali without the help from other siblings. By being the caregiver for her mother, it resulted in no work income. Yet, her children still needed money for college. Mali also experienced stress as her husband was angry about Mali's limited family time. Mali did not know how to resolve the problem of a discontent husband and balancing family/care responsibilities.

Kajohn monitored the patient and when Mali was cooking or doing other routine tasks. Mali always feared that the machine would malfunction ending in mother death. When critical situations (electrical outages or deteriorating patient symptoms) arose, Kajohn could help by using the manual self-platting bag. However, Kajohn usually complained that Mali did not have time to share for him or their children. He sometimes felt bored and angry. Moreover, he worked on the farm alone that resulted in lower income. Higher expenditures were due to home care and children educational costs. Their savings also had been negatively impacted.

Patient Characteristics

The 86-year-old patient was diagnosed with ischemic heart disease and had post cardiac arrest five years ago. As a prolonged ventilator patient, the physician recommended HMV. She now has a tracheostomy with ventilator setting pressure support. This mode augments a patient's spontaneous effort with a pre-set amount of positive pressure. Once the sensitivity setting has been triggered, the ventilator increases the flow to reach the pre-set pressure. The expiratory phase begins when the flow rate drops to a pre-set value. It was IPAP 20 cmH_2O, EPAP 5 cmH_2O, RR 14 breaths/min. She shows TV of 200-380 ml, RR of 16-26 breaths/min, Oxygen saturation of 98 % without signs of dyspnea or cyanosis. Consciousness and orientation are good and communicates by lip movement.

Home Setting Characteristics

The patient's home is located in the village of Tung Lung sub-district, Hat Yai district and 35 km from Hat Yai Hospital. The one story, half-wooden and half-brick house includes five rooms: living room, bathroom, kitchen, two bedrooms, and dining room. The patient's and the caregiver's beds were located in the living room along with the ventilator, oxygen concentrator, and mobile suctioning unit. There is a shelf nearby holding care supplies such as medicines, sterile water, and dressing gauze. There is a patient bell over the bed to signal for help. Curtains surround the patient's bed for privacy.

Payom (พยอม)

Payom is a 23-year-old, college educated single woman as primary caregiver of ventilated father at home without secondary caregiver. She is 2nd of three children of the patient. Four people live in the house including the patient, mother, young brother, and herself. Her older brother work in other province and come back home every weekend while the younger is musician freelance. Her mother is a house wife and not work for earning income.

Payom previously worked as a company employee. She had to quit her job and take on the role of primary caregiver for her ventilated father. After discharging from hospital to home, the family faced not only caring for the ventilated patient, but lacking income, decreasing savings, and rising expenditures. Payom decided to earn income as a rubber tapper. She was exhausted with both roles as caregiver and the main wage earner. She cried often and was overwhelmed with sadness.

Patient Characteristics

The male patient is a 50-year-old paraplegic diagnosed with Guillain-Barre syndrome. In the hospital, he had respiratory failure and needed ventilator support. Once clinically stable, the patient was discharged home with HMV. At home, the patient had good consciousness, on a tracheostomy with a setting pressure control mode ventilator. His breathing was smooth with no signs of dyspnea or hypoxia. Attempts to wean off the ventilator was performed by the caregiver. After one month, he could breathe by himself. In addition, he eventually recovered from his illness, and his physical condition gradually improved. He can now manage daily living, walking, and cycling. Although the patient had prolonged home ventilation, ventilator withdrawal and recovery indicate successful caregiving.

Home Setting Characteristics

The patient's home is located Tung Lan sub-district, Khong Hoi Khong district. The two story half-brick house and half-wooden house included a living room, the patient's room, a kitchen, a bathroom, and stairs leading to the second floor. The patient room had air conditioning, was 16 square meters in size, and glass on three sides. The room contained the necessary medical equipment: ventilator, oxygen concentrator, suctioning, and other supplies.

Kalong (กาหลง) and Chongko (ชงโค)

Kalong is a 64-year-old, sixth grad educated female. She has taken on the role of primary caregiver for her HMV dependent husband (patient). Prior to the illness, Kalong and the patient lived in Pattani province. She ran her own grocery business while her husband was a motorcycle repairman. When the patient had his accident, they moved to his Chongko (daughter)'s house in Hat Yai district. Convenience and hospital proximity were given for the move. However, Kalong had wanted to remain in Pattani.

Chongko is a 43 year old, college educated, married female. Her husband is a policeman, and they have two school age children. She takes care of her father as secondary caregiver at night while Kalong covers day time. Chongko also hired a maid for care, chores and housework. While other siblings, one contibuted to help cover financial care costs while two are college students and could not support. Chongko felt that the finance care was insufficient. The family also to pay for the educational costs of numerous family members.

Patient Characteristics

The patient is a 69-year-old male with spinal cord injuries from a motorcycle accident. He has good consciousness but completely paralyzed and ventilator dependent. He could only move upper neck and lips. The patient has a tracheostomy with HMV setting control mode of IPAP 18 cmH_2O, EPAP 5 cmH_2O, RR16 breaths per min, and TV of 300 ml. Muscular atrophy is the family's main concern. Physical therapy is a non-issue.

Home Setting Characteristics

The patient's house is located in KuanLang sub-district, Hat Yai district and 9 km from the hospital. The house is a modern, two-story brick-house. The first floor includes a living room, dining area, two bedrooms, kitchen, and bathroom. The patient's bed is in the living room and close to the window. There is a TV and sofa near the patient's bed. Adjacent to the patient's bed are ventilator, oxygen concentrator, mobile suctioning unit, and a shelf for supplies.

Saiyhud (สายหยุด) and Kaew (แก้ว)

S*aiyhud* is a 78-year-old divorcee. She has taken on the role of primary caregiver of her son since he has on HMV (two months). Previously giving care for the patient, she was a part time employee at the Shoot Planting Center Royal Forest Department in Chalung – very close to her home. Saiyhud, is a slim woman who was wearing a corset - a sarong-like skirt. Her hair was rolled in the back. The 6th grade educated Saiyhud and her son were living in her cousin's home. Her cousin Kaew is the secondary caregiver. Saiyhud's original home could not accommodate due to distance and electrical issues.

Kaew is a 60 year old, high school educated divorcee. The government retiree Kaew began a second career as a rubber tapper but now has taken on the role of secondary caregiver. He is the patient's uncle and a cousin to Saiyhud. Kaew extended an invitation to Saiyud and her son to live at his house. His house was convenient and central to the hospital and to other family members. Kaew also encouraged and supported the patient to wean off the ventilator successfully.

Patient Characteristics

The 34-year-old patient was diagnosed with myasthenia gravis. In the hospital, he had severe weakness, could not move, and needed a ventilator. At home, he had a tracheostomy with ventilator pressure setting support mode of IPAP 18 cmH_2O, EPAP 5 cmH_2O, RR of 14 breaths per min. One month later, he had tried weaning off with his respiration improving to RR 16-24 breaths per min, TV 300-450 ml., oxygen saturation of 98%, and no signs of hypoxia and cyanosis. He also had a effective cough and could drain secretion by himself. Finally, he was taken off the ventilator and could breathe room air. This is an example of a successful caregiving case of weaning off the ventilator after one month home.

Home Setting Characteristics

The house is a two-story half-wooden and half-brick house, locate in Rattaphum. The house is surrounded by trees and close to Kaew's mother's house. The front of the house has a patio. The first floor includes a living room, dining area, and bedroom. The patient's bed is located in the corner of the living room with easy access to: ventilator, mobile suctioning unit, and oxygen concentrator. Adjacent to the patient's bed are the caregiver's bed and shelving for keeping supplies: gloves, gauze, suction catheters, and medical food. A TV is present to make the patient feel entertained and comfortable.

Kulab (กุหลาบ)

Kulab is a 70-year-old, college educated widow. She has taken on the role of primary caregiver for her HMV dependent mother. She doesn't have any children. She had underlying hypertension and status post spinal discs surgery. Since retiring from a government teaching career, Kulab has lived with her mother and provided care for her. Kulab is the 2nd of six children. In addition, her oldest sister is single and has taken on the role of secondary caregiver. She can adequately substitute for Kulab when Kulab is unavailable or busy.

Patient Characteristics

The patient is a 97-year-old female with underlying ischemic stroke and bedridden at home. She was admitted to the hospital and diagnosed with aspiration pneumonia and sepsis. She was recommended for HMV care. He is now unconscious and on tracheostomy with ventilator - of IPAP 20 cmH_2O, EPAP 5 cmH_2O, RR 16 breaths per minute. She has no signs of dyspnea or hypoxia. Sputum was clear and low volume.

Home Setting Characteristics

The patient's house is located in Pawong sub-district, Meung Songkhla district and 20 km from Hat Yai Hospital. The home is a modern, two-story brick house. The first floor includes an open area, living room, patient's room, kitchen, and one bathroom. The patient's room is air-conditioned, glass-walled, 16 square meters in size, and has a large open window for ventilation. The patient bed is in the middle of the room surrounded by medical equipment: ventilator, oxygen concentrator, and suction device. Nearby is a shelf for medical supplies. The caregiver's bed is also in the room. The patient's room was renovated to isolate the patient from potential infection and human contamination.

Pikul (พิกุล)

Pikul is a 55 year old widow with a primary level education. She has taken on the primary caregiving role her HMV dependent father for more than six months. She has a son and daughter who live at home. The daughter is married while the son is in college and returns home on weekends. Pikul has never done caregiving previously. She has taken this role with two reasons. First, her house is a central location for her other siblings. Second, the other siblings have jobs outside their homes. She can stay at home and her daughter can help provide care for the patient. Pikul can coordinate the schedule to provide care at home - two persons per day which makes her feel less restricted and comfortable to run errands. The family also share care expenses.

Patient Characteristics

The patient is a 90-year-old male diagnosed with stroke and pneumonia. In the hospital, he got sepsis and a lung infection that later caused prolonged HMV. He is now on a tracheostomy with ventilator setting mode of CPAP 5 cmH_2O with Oxygen 5 LPM, and no signs of dyspnea or hypoxia. The patient is conscious, eyes open, and easily follows commands such as hand and head movement. Motor power test was moderate - grad three left side meanwhile right has hemiplegia. The Patient's wife lives in a difference house and comes to visit the patient daily.

Home Setting Characteristics

The patient lives in Padang Basa sub-district of Sadaow district and is 56 km from Hat Yai Hospital. The home is a one-story brick house. The area around the house has trees, good ventilation and shade. The house is clean with a relaxed atmosphere. The patient bed is the corner of living room and near the window. Ventilator, oxygen concentrator, and suction machine are close with easy access. A shelf is stacked with supplies. In the living room, TV and sofa are on one side with two bedrooms on the opposite side. The bathroom and kitchen are past the living room.

Pradoo (ประดู่) and Fuengfah (เฟื่องฟ้า)

Pradoo is the 33 year old, unmarried, older brother of the ventilated patient. Pradoo has a secondary level of 6th grade education. He had a traumatic brain injury and craniotomy eight years earlier. Pradoo has now recovered from his illness and enjoys a normal living. He has taken on the role of primary caregiver for the last 10 months, because he doesn't work and his mother requested Pradoo to be the caregiver. The mother covers all family costs including patient costs. She has been living overseas with her new family but calls every day to Pradoo asking about the patient's status. In addition, the mother comes home once a year and exerts her family influence.

Fuengfah is a 28-year-old college educated woman. She is the patient's wife and functions as the secondary caregiver. Fuengfah also has a baby and works at the local minimart. Some of her duties include wound care and patient food prep. But the majority of the duties are performed by Pradoo as the primary caregiver.

Patient Characteristics

The 30-year-old male patient had post cardiac arrest due to heart failure. The patient can open his eyes but cannot follow commands, Rt. pupil 6 mm., Lt. pupil 3 mm. and normal reaction to light. Decortication and joint stiffness were found in both arms and was unresponsive to pain. He didn't have any pressure sores. He was on TT tube with ventilator RR 13, IPAP 20, and EPAP 8, TV as 250-350ml and low volume secretion. The patient did not have any signs of dyspnea or hypoxia.

Home Setting Characteristics

The patient's home is a contemporary one-story brick house consisting of a living room, three bedrooms, kitchen, and bathroom. The home is located in Khuan Niang district, 400 meters from Khuan Niang Hospital and 39 kilometers from Hat Yai Hospital. The patient resides in the corner of the living room. His bed is adjacent to the window. The medical equipment (ventilator, mobile suctioning unit, and oxygen concentrator) are easily accessible. There is also a shelf holding care supplies: suction catheter, gauze for wound dressing, normal saline, etc.

Banchuen (บานชื่น) and Sangchan (แสงจันทร์)

Banchuen is a 32-year-old divorcee and the primary caregiver of for her younger brother who is ventilator dependent. She also has an older married sister, but and she lives in another district. The older sister also provides some financial support for suction catheters, diapers, and patient transportation. Previously, Banchuen and her mother worked as rubber tappers. Today only the mother continues to work in the rubber fields as Banchuen has to provide care for her brother at home. As a result, household income is low and inconsistent. Banchuen feels stressed and socially confined.

Sangchan is a 66-year-old widow and mother of the patient. She has taken on the role as the secondary caregiver. Sangchan provides only general care such as feeding by mouth, bathing, and monitoring the ventilator tube. For complex and technical issues (suctioning, wound care, and ventilator control), Banchuen handles them. Sangchan's 6th grade education probably factors into her feelings of incompetence and uncomfortability.

Patient Characteristics

The 29-year-old patient has Duchenne muscular dystrophy. This genetic disorder is characterized by progressive muscle degeneration and weakness with chest wall and pulmonary abnormalities. The non-mobile patient was diagnosed when he was eight years old. Recently, he was admitted to the hospital with sepsis and pneumonia. The physician then suggested home care with HMV. He now has a tracheostomy with ventilator settings of IPAP 18 cmH_2O, EPAP 5 cmH_2O, RR of 16 breaths per min., TV of 250-300 ml. and oxygen saturation of 97%. The patient is presently unable to wean off the ventilator due to fear and anxiety about weaning.

Home Setting Characteristics

The patient's home is located in Klong Pea sub-district, Chana district and 36 km from Hat Yai Hospital. The home is a one-story brick house with a terrace is front. Inside the house, there are five rooms: a living room, kitchen, bathroom, and two bedrooms. The patient's bed is in the living near the window with ventilator, oxygen concentrator, and mobile suctioning unit nearby. Adjacent to the patient's bed are the medical supplies and the caregiver's bed.

Koon (คูน)

Koon is a 57-year-old, college educated, married male. He is the primary caregiver for his wife and works as a hotel accoutant. He has two daughters one who is a college graduate and the other one in college. Before his wife got sick, she had run a laundry service at home. The domesticated Koon and his out-going wife had very different life styles. Koon stayed at home cooking and reading while his wife preferred traveling, shopping and meeting friends. Koon had been very willing and open to their different lifestyles.

When his wife became ventilator dependent, she remained at the hospital due to family work obligations. Once at home, Koon negotiated equipment and supply rental/purchase agreements. Caregiving assignments were determined by time of day. A famliy cousin handled day-time hours while Koon and his older daughter took over responsibility at night.

Patient Characteristics

The 60-year-old female patient had asthma for over 10 years and was on inhalation medicine. She suffered an asthmatic attack and cardiac arrest. Post cardiac arrest lead to prolonged ventilator use. At home, she was unconscious, unresponsive to pain, had joint stiffness, and on a ventilator with settings of IPAP 16 cmH_2O, and EPAP 5 cmH_2O. Her breathing was smooth with no signs of dyspnea or hypoxia. She had low secretion volume.

Home Setting Characteristics

The patient is located in Hat Yai Nai sub-district, Hat Yai district, two km from Hat Yai Hospital. The two-story townhouse has a big mango tree in front. Inside the home, there is an open floor plan consisting of an open area, kitchen and bathroom. The patient bed is in the corner of the living room with a ventilator, oxygen concentrator, and mobile suctioning unit close at hand. A small shelf houses all the necessary supplies. Excellent ventilation and optimal lighting help create a relaxed feeling of ambience.

Bunnak (บุญนาค)

Bunnak is a 55-year-old married male who is the primary caregiver for his ventilated mother at home. He has a secondary level education and the youngest of four children. His other siblings are married and live in other provinces. They are unable or cannot provide care for the patient. Bunnak is a fireworks business owner. However, his work provides a low level of income. Taking care of his ventilated mother at home, he occasionally needs to borrow money from other siblings or neighbors.

Patient Characteristics

The 82-year-old mother is a ventilated patient at home due to aspiration pneumonia. The patient has a left hip fracture and needs daily living support. She has breathing problems and was diagnosed with aspiration pneumonia. As a result, she had a tracheostomy procedure and now requires ventilator support at home - setting assist/control mode IPAP 16 cmH_2O, EPAP 5 cmH_2O, and RR 16 breaths per min. Her respiration is normal with no signs of dyspnea or cyanosis, TV of 300-400 ml, and an oxygen saturation of 97%. She is conscious and can follow simple orders such as opening eyes, moving hands, etc.

After being at home for three months, the patient's breathing improved, and she could breathe without the machine for set periods of time. However, Bunnak woke up one morning at 5:00am and found that his mother had died. He last checked on her at 11 pm the previous night. The researcher interviewed Bunnak one year post death. Yet, the researcher had been to their home three previous times during home ventilation and had taken field note recordings. Consequently, the researcher had sufficient information about this care situation.

Home Setting Characteristics

The house is located in Bang Klam district, one story brick-house that far from Hat Yai hospital about 10 km. Insight home, patient lives in open space room which is a living room. Her bed is set in the middle of the living space and close with ventilator, mobile suctioning, and oxygen concentrator. A small table and shelf for keeping caring supplies such as gauze dressing, sterile are surrounding patient's bed etc. TV and wooden sofa are also found as in this area.

Mhok (โมก)

Mhok is a 44-year-old, college educated, married man who took on the role of primary caregiver. Mhok is a construction business owner. Due to his financial success, He hired a maid to handle the labor tasks for his HMV mother. He directs and coordinates all decision-making regarding the patient. He makes his presence felt through his involvement and interaction on a daily basis. Mhok's sister also contributes financially, but her work as an accountant keeps her away from visiting the patient often. This particular case is different from the other cases as it involves a paid caregiver due to higher socio-economic standing. Yet, Mhok is intimately involved with patient care details and decision-making.

Patient Characteristics

The patient is a 63-year-old female with a post traumatic brain injury and craniotomy - unconscious and unresponsive. Aspiration pneumonia was diagnosed and believed to be the main cause of prolonged ventilator use at home. She has a tracheostomy with HMV settings of PCV mode IPAP 20 cmH_2O, EPAP 5 cmH_2O, and RR of 16 breaths per minute. The patient is quite fat obese, yet, with no pressure sores. The patient is on a feeding tube.

Home Setting Characteristics

The patient's home is located in TaKam sub-district, Hat Yai district, and 19 km from Hat Yai Hospital. The half-wooden and half-brick house is located on a rubber plantation and quite far from the main road. The renovated patient room is 16 square meters in size with the bed in the middle and the ventilator, oxygen concentrator, and mobile suctioning unit nearby. A small shelf holds the medical supplies. The room is clean with good ventilation and optimal lighting.

Unchan (อัญชัญ)

Unchan is a 59-year-old, high school educated single woman. She is the third of six children. Unchan and her older sister live and work together as street food sellers. They have taken their mother into their home. After the mother was discharged to HMV care, Unchan took on the role of primary caregiver. Her sister assists in care procedures or when Unchan has other responsibilities to conduct. Their brother also provides money to support care costs. Unchan has never thought of her mother as a burden. She and her siblings have been more than willing to care for their mother.

Patient Characteristics

She is a 97-year-old Chinese-Thai woman with underlying dementia. In the hospital because of a hip fracture, she developed sepsis and respiratory failure believed to be caused from pneumonia. She was discharged home once clinically stable. At home, she has a tracheostomy with ventilator settings of CPAP mod with no signs of hypoxia or dyspnea. Throat secretion was low volume and clear.

Home setting Characteristics

The home is located in Hat Yai Nai sub-district, Hat Yai District, and six km from Hat Yai Hospital. The house is a one-story wooden house. The 20 square meter patient room was renovated with brick and glass and air-conditioning. A sofa, TV, and medical supplies reside in this room. The patient bed is the middle of the room with ventilator, mobile suctioning unit, and oxygen concentrator nearby. At night, Unchan and her sister both sleep next to the patient bed. During the day, the patient’s room functions as a living room where friends and family can mingle and socialize.

Ratree (ราตรี)

Ratree is a 60-year-old, married woman with a 6th grade education. As the family's 2nd child, she has taken on the role of primary caregiver of her mother for the last four months. Previously, she was a farmer and rubber tapper, but this new caregiving role has eliminated her income. Other children of the patient lacked confidence and comfortability to provide technical care such as suctioning, weaning, dressing wound, and maintaining the machine. Her siblings can help in routine hygiene tasks such as feeding, change body position, and bathing. Ratree often felt overloaded and stressed within the caregiving role.

Patient Characteristics

The 83-year-old female patient is diagnosed with ischemic stroke, right hemiplegia. She is conscious and orientated and can easily follow commands (head and hand movements). She has now on tracheostomy with ventilator settings of CPAP 8 cmH_2O, oxygen 5 LPM. There were no signs of dyspnea or hypoxia. Throat secretion had low volume and clear.

Home Setting Characteristics

The patient's home is in TungLan sub-district, Klong Hoi Kong district and 24 km from Hat Yai Hospital. The one-story brick house with a front terrace is surrounded by many trees and a rubber tree farm. Inside the home are five rooms: a living room, two bedrooms, kitchen, and bathroom. In the living room, the patient's bed is close to the window with the machinery nearby: ventilator, suctioning device, and oxygen concentrator. A shelf for medical supplies is next to the ventilator. The house has good ventilation, felt cool even without fans.

Lamduan (ลำดวน)

Lamduan is a 39-year-old college educated, married woman. She is the youngest of three children. She and her husband have a silver plating business at home. The household income is sufficient enough to cover expenditures, but she has no savings. They also have one pre-school age daughter. Lamduan has taken on the role of primary caregiver. One brother is married and lives far away while the other one is single. The single brother had an ischemic stroke and lives in the same house. Every day she has many duties such as providing patient care, taking care of her husband and daughter, and going to work. She experiences a lot of stress but keeps on pushing forward.

Patient Characteristics

The 64-year-old female patient had a stroke and pneumonia. At home, she is on a tracheostomy tube with ventilator settings of IPAP 16 cmH_2O, EPAP 5 cmH_2O, RR 16 breaths per minute, and no signs of dyspnea. Her TV was 250-300 ml, Respiratory 24 breaths per min. and oxygen saturation of 97%. The patient has good consciousness, eyes open, and can follow commands. Her left side is weak and has restricted movement.

Home Setting Characteristics

The home is located in Ta Kam sub-district, Hat Yai district and 17 km from Hat Yai Hospital. Two relative houses surround the main home. The patient's home is a one-story brick house with the main entrance in the back. Rooms include a living room, bathroom, and two bedrooms. A terrace is also found in the front of the house Lamduan's husband works. The patient's bed with ventilator is in the living room near the window. There is a small table for medical supplies such as a mobile suctioning unit, oxygen concentrator, and other supplies. The sofa and TV are also found in this area.

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